ABSTRACT

Nurses frequently care for people who have experienced seizures, as clinical specialists, as primary care providers, at the bedside, or in the community. Because of these diverse roles and practice settings, nurses can be instrumental in educating newly diagnosed patients, their families, and caregivers about key aspects of living with epilepsy, ranging from basic safety fundamentals and seizure first aid to managing complicated medication regimens. Yet, the emotional ramifications of a new diagnosis of seizures must not be overlooked. Nurses need to be cognizant of how to assist each individual to adjust and even excel within the context of this diagnosis. A caring and competent clinician can assist patients in maintaining a sense of control and taking charge of their lives.

Nursing care extends beyond the initial diagnosis to helping people establish their goals for treatment and design a plan, in collaboration with their healthcare team, that is the best fit for them in terms of their particular seizure type, age, gender, comorbid conditions, and quality of life. Self-management programs are increasingly popular for managing chronic disorders such as epilepsy. This approach broadens the scope of medication management from a medical view of compliance and incorporates the many factors that influence a person’s ability to take medications and follow lifestyle changes over time. Self-management plans also require effective communication and individualized treatment plans, recognizing that epilepsy is not a “one size fits all” disorder. Nursing strategies to enhance medication self-management may range from teaching people how to assess risks realistically, how to monitor seizures and treatment effects, or exploring ways to reduce the complexity of medication regimens. (Adv Stud Nurs. 2005;3(3):85-90)

Approximately 181,000 people each year are diagnosed with seizures in the United States, and about 150,000 of these will develop recurring seizures, otherwise known as epilepsy. For most individuals living with epilepsy, medications are central to seizure control. In a study by Kwan and Brodie of 470 newly diagnosed epilepsy patients, 47% became seizure-free on the first antiepileptic drug (AED) tried, with over 90% doing so at modest to moderate dosing. Almost two thirds of the participants responded to the first 2 drugs. Yet it may take years for some people to find appropriate care and respond to a medication. A recent study of people with partial seizures found an average of 9 years from time of diagnosis to time of failure of second drug. These data suggest that for many people the first drug tried may be the only one, or it may take years to consider other options, thus selection of AEDs and teaching to enhance the success of medication trials is critical in the early years of living with seizures.
Often, the first person a patient may come in contact with is a nurse in the emergency room, an inpatient medical or neurology unit, school or work settings, or outpatient clinics. Patients are usually not referred to epilepsy nurses for education or counseling until late in the course of their illness, when seizures become difficult to control or psychosocial problems develop. However, many “teachable moments” occur between patients, family members, and nurses at the time of diagnosis that provide valuable opportunities for education.

Initial interactions often focus on the diagnostic process and managing acute seizures, as seizures in adults are often a symptom of another medical or neurological problem. For example, adults with new-onset seizures may present for treatment of a stroke, brain tumor, or head trauma. Nevertheless, nurses may be involved in the prescribing or administering of AEDs, while others will be involved in monitoring responses to treatment. Understanding long-term consequences and safety issues of AEDs, in addition to factors that affect a patient’s ability to manage his/her medications will be necessary for effective management of seizures.

Specifically, the nurse may review the regimen with the patient, assessing for adverse effects, drug interactions, or scheduling conflicts that may impact compliance. If breakthrough seizures occur prior to changing medications or increasing dosages, it is particularly important to determine whether the patient is actually taking the medication as directed, and if not, why. Teaching patients and families about how medications work, simplifying regimens, and counseling to change behaviors are just a few examples of simple strategies that can improve compliance and seizure control.

**LIVING WITH EPILEPSY—FROM COMPLIANCE TO SELF-MANAGEMENT**

Often, patients diagnosed with a serious and sometimes frightening condition like epilepsy have a tendency to presume that they need to “do what the doctor orders.” Or they may be considered a “difficult” or “non-compliant patient” if they question decisions, ask for more information, or take actions that may be different than what was prescribed. This focus on compliance usually presumes the doctor or nurse is right, and the patient is wrong. Medication factors, such as the frequency of doses, number of drugs, or medication side effects, affect compliance, yet each person’s situation is unique. Epilepsy is not a “one size fits all” disease, thus, trying to make patients adhere to a “one size fits all” management plan usually does not work.

On the other hand, self-management approaches encourage active participation and decision making on the part of the patient and family and focus on the steps a person must take to manage their seizures and the consequences of epilepsy effectively. While multiple medical and lifestyle issues are incorporated into self-management theories or programs, medication management has been considered a key component by many researchers.

Similar to other chronic disorders, self-efficacy, or self-confidence, and patient satisfaction have been identified as important predictors of successful self-management, particularly of medication management. Self-efficacy is also affected by a patient’s social

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**Self-Management**

- Broader view—multifaceted causes and components
- Behaviors needed to manage medications successfully and make informed choices
- Tailored to individual goals and problems
- Focuses on active participation, decision making
- Fosters trust, respect, and empowerment
- Key factor—self-efficacy


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**The Importance of Identifying Patient Goals**

- Patient perspective of efficacy and side effects of
  - Different therapies
  - Monotherapy
  - Polytherapy
  - Nonmedical or alternative therapies
- Consider impact of therapy with regard to
  - Age
  - Sex
  - Drug interactions
  - General health
  - Comorbid conditions
  - Reproductive function
  - Safety and falls

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support, depressive symptoms, and perceived stigma; a patient’s self-confidence in turn influences what patients expect to happen as a result of seizures and treatment. These complex relationships highlight the need for nurses to broaden their view of patient education, and incorporate strategies that will build self-confidence, improve satisfaction with care, set appropriate expectations and goals, and address problems such as depression and stigma.

**Establishing Goals and Expectations**

In expanding into this new role, the nurse may help patients and families to first explore their goals and expectations, including the importance of seizure control, treatment side effects, and changes in quality of life. This approach requires nurses to truly be patient-centered, and tailor treatment plans to help patients achieve their goals (see Sidebars). For example, patients may not be concerned about drug interactions, but instead may wonder whether being on these drugs will affect their cognitive abilities, mood, or energy level. The nurse, however, can help the patient consider what steps would help prevent problems in these areas, one of which may be to avoid or minimize certain drug interactions. Likewise, the importance of absolute seizure control may differ from person to person. For some individuals, perhaps it just means staying safe—finding a drug that may not provide complete control, but causes fewer side effects. For others, it means becoming seizure-free and being able to obtain a driver’s license again. Still other patients may be interested in alternative therapies, or nonmedical interventions.

Exploring the meaning of control is a critical first step, and must include the importance and risks of poor seizure control and the risks of treatment side effects if aggressive control is sought. Instead of just offering one AED to a patient, the nurse should explain all available options that are appropriate for their condition, and help him/her weigh the pros and cons of the side-effect profiles in an informed manner. This approach allows the patient to make informed decisions in partnership with his/her provider, and have appropriate expectations for the treatment regimen.

**Assessing and Counseling for Risks**

It goes without saying that the newly diagnosed patient with epilepsy needs to be aware of seizure first aid, how to prevent injuries, and the impact of seizure occurrence on driving. However, the occurrence of seizures may raise other questions about epilepsy-related risks that will impact decision making. Risk assessments must try to address those factors that might be prevented by better seizure control, those that may be exacerbated by AED side effects, or problems that may be independent of seizures. Counseling about medication and seizure risks should include the probability that they will be taking AEDs for the long term, the consequences of stopping medications prematurely or missing medications, and risks of status epilepticus or serious injury. Some concomitant medications, such as some of the antibiotics (eg, ciprofloxacin) and antidepressants, can increase risk of seizure breakthroughs. Other medications may interact with AEDs, causing neurotoxicity; the interaction between erythromycin-type antibiotics and carbamazepine is just one example. These medication-related risks are examples of risks that nurses assess on a regular basis, and should be incorporated into patient teaching about seizure and medication management.

Central to risk assessment is helping patients and families understand that causes of many risks are not known or may be due to both seizures and possibly side effects of AEDs. Cognitive and mood problems are just 2 examples of this dilemma. Cognitive impairment may occur from the underlying etiology, be affected by location or frequency of seizures, be part of a seizure, or occur as a result of certain AEDs. Mood changes are equally if not more complex. Episodic changes in mood can occur as part of a seizure event (before, during, or after a seizure), while other mood changes may be more prolonged and occur apart from the actual seizure. The contribution of seizures to the occurrence of problems is often unknown, but underlying dysfunction in areas of the brain critical for regulation of mood suggests the interrelatedness of these problems. Both older and newer AEDs can affect mood; some have positive mood-stabilizing effects, while others can cause mood swings, irritability, or symptoms of depression or anxiety. Thus, nurses must be attuned to the complex brain-behavior relationships underlying cognitive and mood disorders in order to assess these problems and counsel patients appropriately.

The occurrence of seizures and the use of AEDs may affect health status in other ways and will be part of risk assessment and decision making. Both men and women with epilepsy may display greater than expect-
ed problems with sexual function or may experience reproductive endocrine problems that can have far-reaching implications. The causes of these gender-specific health concerns must be evaluated individually, as their occurrence may be related to alterations in the neuroendocrine system from the seizure disorder or side effects of certain AEDs.11-13 Teaching patients about these potential risks and causative factors will help them have more realistic expectations about what may be changed by treating seizures, and what factors may be due to pre-existing conditions and those that require other treatments.

People often worry about the risk of dying, but this is rarely discussed, and if it is, preventable risk factors are not explored. While discrepancy exists regarding many risk factors, poor seizure control, other neurological problems, and tonic-clonic seizures are associated with increased mortality.14 As concerns about dying are identified, nurses can help patients start a dialogue with their physician and explore their personal risks and preventable factors such as seizure control.

Likewise, another focal point for counseling concerns the risks versus benefits of monotherapy as compared with polytherapy. It is common practice to aim for using one AED whenever possible to control seizures, as the use of multiple drugs usually increases side effects and the potential for drug interactions, particularly when older AEDs are used.15 Yet many people with refractory seizures or multiple seizure types require more than one drug for optimum seizure control. Given similar efficacy profiles of many AEDs, selection of drugs should consider individual patient characteristics in relation to AED tolerability, risks, and impact on quality of life.16

Over time, the patient and his/her family can work with the nurse to take a personal inventory of the patient's epilepsy and overall health and use this to ascertain what is most important. This inventory helps patients weigh the risks versus benefits of different options and the degree of risk he/she is willing to accept. The personal inventory should incorporate the importance of seizure control and medication side effects as well as any comorbid conditions or problems the patient is experiencing. Since this process will occur over time, one of the most helpful strategies is to connect patients with resources that provide credible and reliable information and support that can be accessed as needed. Revisiting this risk assessment periodically will allow opportunities for patients and families to reassess their situation, ask questions as their seizure experience or health changes, and change their treatment plan as needed (see Sidebar).

### Elements of Risk Assessment

- Personal inventory
- Weigh benefits and risks
- Explore options to minimize or prevent risks
- Make informed choices

### MAINTAINING SELF-MANAGEMENT—STRATEGIES TO MONITOR SEIZURES AND MEDICATION SIDE EFFECTS

Asking questions and active listening for the patient's perceptions of change is most helpful and will actively engage him/her in the monitoring phase of treatment. Once patients have a starting point, nurses are instrumental in teaching patients strategies to monitor whether their treatment plan is working. Since the treatment of epilepsy is based to a large extent on self-report of symptoms that occur outside of the physician's or nurse's office, having patients document and share information about seizure occurrence, problems with medications, or missed doses is critical. A variety of techniques are available to help patients monitor their symptoms at home, such as simple calendars, checklists, questionnaires, and personal digital assistants. Which technique will be most appropriate depends on the patient's literacy level, comfort with technology, time, motivation, and cultural background. Validating the importance of patient-collected information should be routinely done by reviewing this information with the patient at the bedside, during clinic visits, or by telephone.

Subjective data must then be supplemented by objective monitoring. Physical examinations can identify focal neurological signs or symptoms of neurotoxicity. Nurses with prescriptive authority may order and interpret diagnostic studies such as electroencephalograms, computed tomography scans, magnetic resonance imaging scans, or blood studies. All nurses should understand the reasons and implications for diagnostic studies and be able to use these results in patient care and teaching. For example, blood studies
such as therapeutic drug levels may be used to assess if the dose of AED is too low or too high, verify neurotoxicity, or assess compliance. While these drug levels can be helpful for monitoring older AEDs such as carbamazepine, phenytoin, valproate, or phenobarbital, their utility with some of the newer AEDs is uncertain, as the clinical significance of laboratory ranges is more variable. Neuropsychologic testing may be helpful to assess complaints of cognitive dysfunction, separating deficits that may be related to the underlying brain impairment from symptoms due to AED side effects. When a patient’s ability to drive is uncertain, driving evaluations may help assess the contribution of cognitive or functional problems that affect safety and driving abilities.

During the monitoring phase, it is important to substantiate findings, whenever possible, with family members or caregivers. What is their perception of change? How is the treatment affecting the patient functionally? What new problems have occurred? With the patient’s permission, insight from others is vital, particularly if a patient has cognitive or language deficits that affect their ability to remember or communicate concerns or problems. Offering a variety of monitoring methods, listening to the patient, and reassessing the effectiveness of monitoring can enhance a patient’s self-confidence and ability to manage his/her seizures. When patients are having difficulties accomplishing these tasks, encouraging more help from family, friends, or other caregivers may provide critical social support (see Sidebar).

**PROCEEDINGS**

**Strategies to Monitor Seizure Frequency and Side Effects**

- Calendars
- Checklists
- Computer, PDA
- Questionnaires
- Physical examination
- Blood tests
- EEG studies
- Neurophysiologic testing
- Driving tests
- Talk and listen to patients, family, and caregivers

PDA = personal digital assistant; EEG = electroencephalogram.

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**MEDICATION COMPLEXITY—
A CASE-IN-POINT FOR SELF-MANAGEMENT**

Perhaps the most important area for self-management for people with epilepsy is medication management; adherence to their medication regimen is one aspect of this task. While researchers have identified many factors that may affect adherence, the complexity of medication regimens has not been studied in depth. Medication complexity involves more than just the number of medications; frequency of dosing, administrative actions, and special instructions necessary to take medications regularly are often overlooked for their contribution to complexity17 (S. O. Kelley, unpublished data). Complex regimens can be a barrier to compliance, which in turn impacts on seizure control. For example, taking medications 3 or 4 times a day has been shown to dramatically affect compliance rates in people with seizures.18

Barriers to compliance such as cost, forgetfulness, or difficulty accepting epilepsy and need for treatment must first be addressed. However, strategies to simplify regimens should also be explored. Taking fewer drugs may lessen costs, while simpler regimens are easier to remember and implement. Strategies may include working with physicians and patients to reconsider the number of drugs, to try AEDs that may help achieve multiple effects, to decrease the number of doses needed per day (by using extended-release formulations, if available), and provide reminder tools (eg, timers, calendars, special pill boxes).

Medication complexity has been examined in more depth using the Epilepsy Medication and Treatment Complexity Index (EMTCI); this tool examines 3 areas related to medication compliance—medication frequency, special instructions the patient may have to follow (eg, having to take their drug at a different time than their other medications or at specific times), and administrative actions such as having to cut a pill in half before ingesting it, or taking different dosage strengths or more than one tablet at one time.17 In a recent study evaluating self-management behaviors of people with epilepsy, the EMTCI was administered to 317 participants at 3 US sites (2 epilepsy clinics and 1 general neurology clinic). While the average number of pills per day was 8, the range was 1 to 36 for all participants. Monotherapy was used most frequently (44%), however, 34% took 2 AEDs. The number of medications correlated with medication complexity.
Slightly more than half of study participants were taking their medicine twice daily; however, their doses often differed throughout the day, adding another layer to complexity. Some also were required to take medications at different times from other AEDs, to take them with food, or to adjust their dosage according to whether they had experienced a seizure.17

Understanding the complexity of medication regimens from the patient perspective can offer valuable information for nurses to tailor medication management. Older individuals, who may have limited support systems or other deficits that impact medication management, may be particularly vulnerable when faced with complex AED regimens. Likewise, children who are not able to implement complex regimens independently will require strong nursing support to help them successfully integrate all of these complexities into their daily lives, or find alternative ways to manage their treatments successfully.

CONCLUSION

For all individuals with epilepsy, the nurse can be instrumental in helping design and tailor self-management approaches that empower patients and families to be active participants in the patient’s care. The first step is to take a personal inventory of one’s goals within the context of the risks and benefits of pursuing a particular goal. Next, because medications are the focal point of seizure management for the majority of people with epilepsy, nurses can help patients to simplify their pharmacologic regimens and eliminate potential drug interactions. Once a management plan is in place, the nurse can assist in building the individual and family to build their self-confidence by teaching skills for taking medications successfully, monitoring information needs, communicating with his/her treatment team, and incorporating these plans into daily life. Critical to the success of any treatment plan is ensuring follow-up and support. Nurses can assist in identifying needs and connecting patients and families with community support systems such as the Epilepsy Foundation or other social service organizations that can supplement the available professional and family support. Nurses will wear many hats—as first-line providers, liaisons to other specialists, consultants, and educators. Unique to the nursing specialty is the need to be a good listener, because to be an advocate and foster patient empowerment, one needs to hear the message.

REFERENCES