ABSTRACT

The onset of epileptic seizures in adults often raises many questions and concerns that affect a person’s quality of life. Seizures and prescribed treatments may have a greater impact on a patient’s quality of life than healthcare providers realize. Recently published practice parameters for treating new-onset epileptic seizures in adults stress the importance of individualizing treatment. Yet, a person’s quality of life is affected by many factors, particularly mood and health status, which must also be assessed and treated aggressively. The nurse’s role in providing the art, in addition to the science, of individualizing care is critical to this process.


A new onset of epileptic seizures is a confusing time for all involved. Whereas healthcare providers try to determine what happened and what to do next, patients and families are often left to wonder why it has happened. The fears of having further seizures, sustaining injuries, or even dying are not uncommon. Patients also worry about what to do in case they have more seizures; a worry substantiated by recent surveys highlighting patients’ surprising lack of knowledge about the proper responses to seizures. In a representative survey of American adults (n = 4397), only 25% of the participants thought they were knowledgeable about epilepsy and slightly more than 33% knew what to do if someone had a seizure. These worries, fears, and lack of knowledge compound the unpredictability inherent in a diagnosis of seizures and can interfere or color the decisions that patients make about their treatment. This article discusses the impact of newly diagnosed seizures on adults and highlights key factors to consider in the assessment and care-planning process.

CONTROL OF SEIZURES AND RESPONSE TO TREATMENT

In many people, seizures are isolated events or are easily treated with antiepileptic drugs (AEDs). For example, data from 1995 indicate that approximately 60% of 181 000 people who develop seizures and epilepsy each year have seizures that remit or are controlled, whereas 25% of patients will eventually develop seizures refractory to treatment. Several studies are under way to identify predictors of seizure prognosis. Most new-onset seizures are diagnosed in pediatric and elderly patients, but seizures also occur in the adult years and are most often a result of trauma, tumors, or cerebrovascular disease. Certain seizure types and syndromes are more responsive to treatment than others, and recent work has begun to investigate genetic influences to treatment responses. Although medication factors may influence responsiveness, if AEDs appropriate to seizure type are used, approximately 60% of patients with new-onset seizures will respond to the first 1 or 2 drugs used. These findings stress the importance of targeting treatment aggressively and early and of choosing treatments wisely to minimize
any detrimental effects of medications on a person’s health and quality of life.

Quality of Life: The Scope and Consequences

The burdens of living with epilepsy can be enormous and more challenging to many people than the actual seizures. Begley et al found that the indirect costs of living with seizures, as measured by lost productivity at work and home, accounted for approximately 85% of the total costs of epilepsy annually and were greatest for those patients who continued to have seizures. Unemployment rates appear to vary with seizure frequency and are 5 times higher among people with persistent seizures than among those people with controlled seizures. Seizure frequency and having a driver’s license are important factors that affect employment for people with seizures. The occurrence of even 1 or 2 seizures may prevent a person from driving for months to years, with the length of driving restrictions varying according to state laws (visit www.epilepsyfoundation.org for state driving regulations). Unfortunately, many people depend on a driver’s license to commute to work or their work responsibilities may depend on driving. Some people may be able to compensate for an inability to drive, particularly those living in urban areas with accessible public transportation. Others are forced to relocate, change careers, or become unemployed. The impact of these changes can be enormous and may contribute to a patient’s feelings of loss, dependency, financial insecurity, helplessness, and changes in roles and relationships. Although this area has not been systematically studied in people with new-onset seizures, the clinical ramifications are clear.

Many quality-of-life studies have been conducted in people with chronic epilepsy and suggest that quality of life is worse for those patients with poor seizure control. However, comorbid depression has also been identified as a major factor influencing health status and quality of life. A recent study of 87 patients with temporal lobe epilepsy found that interictal anxiety and depression independently affected health-related quality of life (HRQOL) and were more powerful predictors than seizure control. The independent effect of mood has also been noted in a cohort of patients undergoing surgical evaluations (n = 115), with seizure worry and depressive symptoms being the most important factors that affect quality of life. Furthermore, a population-based sampling of people in Texas, using the 1998 Behavioral Risk Factor Surveillance System, found that patients with epilepsy had a worse HRQOL than people without epilepsy, including more physically unhealthy days, pain, depression, anxiety, and less sleep or rest.

The factors affecting quality of life in adults with new-onset seizures are not as well understood. One study evaluated the impact of a single seizure on health status (n = 83). There were no differences in health status between patients who had had a single seizure in the past year and those patients with well-controlled epilepsy or uncomplicated hypertension. Interestingly, patients with single seizures scored significantly lower on tests of vitality and showed trends toward changes in roles and physical function. A Swedish study that evaluated newly diagnosed adults with seizures (n = 41) found that eligible patients (37/41) demonstrated the lowest scores on a “psychological/spiritual” domain.

Additional insight can be obtained from selected studies of quality of life in people with well-controlled seizures. Minimal differences were seen between 397 patients with confirmed epilepsy in Norway and a general reference group (n = 1663). However, people with epilepsy scored lower on 6 of 8 SF-36 scales (36-Item Short Form Health Survey). Although 80% of the patients with epilepsy used AEDs, there appeared to be no differences in health status scores between patients who were taking medication and were seizure-free as compared to those patients not taking AEDs. Other studies suggest that AED side effects may influence some aspects of a patient’s quality of life, even for those patients with well-controlled seizures. Unfortunately, assessing and differentiating the impact of seizures and different AEDs on a patient’s quality of life is difficult because the scales and methodology used vary significantly across studies.

Patient perceptions of epilepsy and of their treatment regimens offer a more detailed view into the components of and the impact on quality of life. A study of subjective experiences of 1023 people with epilepsy drawn from 2 community-based samples (national postal survey and callers to the Epilepsy Foundation) found that fear, depression, or anger were initial reactions to a diagnosis of epilepsy for more than 50% of the respondents. Fear of when the next seizure would occur was cited most frequently (32.2%), whereas problems reflecting social stigma were raised by 23.8% of respondents. Areas perceived as problems from having epilepsy were rated from highest to lowest and included impact on school per-
formance (54%), cognitive function (46%–0%), reproductive concerns (39%), overall quality of life (39%), lifestyle limitations (36%–17%), and factors associated with relationships (32%–21%).

Study participants who were asked about perceptions of epilepsy treatment ranked seizure control, side effects, convenient dosing regimens, and cost among the highest concerns. Problems attributed to adverse effects of medications and cited as having a “large effect” by at least 33% of participants included cognition, energy, school performance, concern about having children, and overall quality of life. Participants also reported concerns ranging from sexual function to coordination, balance, and emotional well-being. When these concerns are combined with other potential health effects of AEDs, such as weight gain or loss, cosmetic effects (eg, hair growth, hair thinning, and acne), dental problems, impaired bone health, teratogenic effects, and potential drug interactions, a patient’s reluctance or fear of taking medications to control seizures is easily understood. However, when medications are chosen, dosed, and taken properly, the risk of many side effects can be lessened or eliminated.

GOALS OF EPILEPSY MANAGEMENT

Controlling seizures has taken on a new urgency as the dangers of repeated seizures on brain function and quality of life are better understood. The epilepsy community has been working more aggressively toward helping people achieve “no seizures and no side effects,” but many challenges and barriers remain, particularly the differences between perceptions of healthcare providers and those of patients. Although seizure control is critical and rated highly by patients in some studies, patients undergoing surgical evaluation reported that changes in social function (eg, work, socialization, driving, and independence) were most important to them. These conflicting findings underscore the need to individualize epilepsy treatment and target the medical and psychosocial concerns for meaningful changes to occur.

MANAGING EPILEPSY: HOW TO CHOOSE?

Helping patients make informed decisions regarding drug selection or when to consider options, such as the ketogenic diet, vagus nerve stimulation, or surgical treatment, remains a challenging area. Unfortunately, people often wait too long to receive needed care, are ill-informed about where or how to seek care, are unaware of treatment options, or have problems accessing care. In a prospective study of 333 patients with partial epilepsy, investigators found an average lag time of 9 years from the time of the patient’s seizure onset to the time that a second drug was considered a failure.

The American Academy of Neurology’s guidelines for the use of AEDs in patients with newly diagnosed epilepsy provide an assessment of the available evidence on the efficacy and tolerability of standard and newer AEDs. Because most patients respond to the first 1 or 2 drugs prescribed, the need to strive for treatment with monotherapy and avoid potential drug interactions was reinforced. Level A evidence for the use of the newer AEDs (lamotrigine, gabapentin, oxcarbazepine, and topiramate) is available, in addition to the use of the standard AEDs (phenytoin, carbamazepine, valproic acid, and phenobarbital). Level B evidence was noted for the use of lamotrigine in children with newly diagnosed absence seizures. This review did not take into consideration the impact of any specific treatment on a patient’s quality of life, but it stressed the need for tailoring treatment in response to drug safety profiles and patient tolerability.

For years, epilepsy specialists have stressed the benefits of monotherapy; however, in practice, many patients continue to be prescribed multiple AEDs. Whereas some patients may require polytherapy for the type or severity of their seizure disorder, other patients report fewer side effects and maintenance of or improvement in seizure control while using one AED. The impact of conversion to monotherapy on quality of life was demonstrated in 2 recent studies involving patients with refractory seizures who experienced positive effects on their quality of life when they were converted from polypharmacy to monotherapy. Subsequent research involving patients with new-onset seizures must explore the impact of medication changes in more detail because finding the right medication is often a matter of trial and error.

Patients with epilepsy and their family members often are not taught how to assess the risks of seizures, the consequences of comorbid conditions, or adverse effects of treatment, thus complicating therapeutic challenges. As a result, people may make incorrect assumptions or have unrealistic expectations regarding their treatment regimen. Educating patients and their families about the assessment of risks and side effects

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and incorporating these findings into decision making is a critical step in epilepsy management. 19

**IMPROVING QUALITY OF LIFE: NURSING ASSESSMENT**

The nurse’s role in caring for patients with seizures varies, depending on the practice setting and the nurse’s frame of reference. When improving the patient’s quality of life is the overall goal, the nursing assessment must be comprehensive and patient-centered. Few studies have examined the impact of the nurse’s role in the care of patients with new-onset seizures. In the United Kingdom, the use of clinical nurse specialists to educate patients with new-onset seizures resulted in the patients feeling that they were receiving adequate information and advice; however, knowledge scores were unchanged from those patients receiving usual medical care.25 Further research is needed to explore whether patients’ use of information differed or if patient satisfaction with care was improved by nursing intervention.

**SEIZURE HISTORY**

Nursing assessment must first explore the presenting symptoms or first seizure. Descriptions from patients, family members, and friends can provide valuable diagnostic information. In addition, the nurse can learn how the patient and their family felt at that time (eg, their first reactions and any lingering concerns and worries). Listening carefully to what is said, in addition to what is not said, is one of the most important skills a nurse can use at this time, as the first seizure leaves an imprint that may shape a patient’s or family member’s responses to subsequent events. Where the seizure occurred or what was happening at that time may provide clues to potential triggers; concomitant illness, sleep deprivation, association with menses or other hormonal changes, or use of other medications, alcohol, or recreational drugs are some possible seizure triggers that are pertinent to the diagnostic process and may be addressed through lifestyle changes, medications, or other management strategies.

**HEALTH STATUS**

Screening for safety concerns and other health conditions must also be incorporated into the assessment process. Cognitive, mood, and behavioral disorders may suggest pre-existing problems or factors that may influence a diagnosis of epilepsy. Coexisting disorders also may affect the selection of treatment and need for monitoring. For example, symptoms of depression should be considered when the clinician prescribes an AED—in this case, an AED that will not exacerbate depression should be chosen. Patients with cognitive problems at baseline may benefit from AEDs that have a low risk of affecting cognition or behavior. Choosing a drug that does not cause weight loss is important for patients who have eating disorders. Similarly, a drug that causes weight gain should not be the first choice for patients who are overweight or have pre-existing cardiovascular problems. Patients with mobility impairment need careful monitoring and safety education to help prevent falls and injuries if the clinician prescribes drugs that affect vision, coordination, or gait. Recognition of these health and functional problems helps the nurse identify learning needs and tailor interventions appropriately. Because mood disorders play a vital role in a patient’s quality of life, early recognition and treatment of symptoms and referral to appropriate supports and counseling should be part of the nursing assessment for all patients with newly diagnosed seizures.

**FAMILY RESPONSES AND COPING**

Treating epilepsy effectively means treating families, often thought of as the “hidden patients,”26 in addition to the person with seizures. Families and friends can offer helpful support and guidance, but they can also be a source of stigma-producing behaviors and reinforce feelings of dependency. Roles and relationships may change as people are not able to carry out their usual responsibilities or as one person becomes more dependent on another. Nursing assessments should explore how epilepsy affects different family members; this information can be used to suggest strategies that foster a more positive family influence or to refer the family member(s) to counseling or support groups to address their concerns more specifically.

**SUPPORTING PATIENT EMPOWERMENT**

Setting goals and making treatment decisions can be difficult, particularly if patients do not understand their diagnosis or what role to take in their own care. Whereas some patients expect the physician to set goals and make decisions, others seek a more central role in decision making or work best with a “shared care” model that emphasizes a working partnership and self-management principles. Self-management is
generally defined as the steps a person takes to manage seizures and their consequences effectively. Patients with new-onset seizures will have many concerns and rely on the healthcare professional for information about epilepsy. The nurse plays an integral role in this education by listening to patients and their families to identify their needs and to set realistic goals. Patients, families, and providers then must agree on common goals and develop a working partnership that supports patient empowerment and ongoing communication.

Assessing seizure control and responses to treatment must occur over time, as patients and providers monitor the frequency, severity, and impact of seizures. Teaching patients how to assess treatment side effects and giving them easy-to-use tools to track changes will give the patient and the clinicians data on which to base decisions. For example, the use of a side-effects questionnaire has been shown to increase identification of toxicity and help guide medication modifications. Questionnaires to track changes in quality of life can also be used, but these should not take the place of ongoing assessments of the patient’s health, functional status, and specific areas of concern.

**Providing Education and Support**

Educating patients about seizure management begins at the first clinical visit as patients are asked critical questions and learn about their diagnosis. The clinician’s use of correct terminology is crucial, thus patients can understand the medical facts about epilepsy and seizures. Seizure first aid, which stresses proper responses to managing seizures and when to call for emergency help, should be taught to all patients with newly diagnosed seizures and reinforced repeatedly to help allay seizure worry and to identify new concerns.

Medication management is usually a central facet of care, yet the needs of adults with new-onset seizures will be much different from those needs of adults with chronic refractory seizures. Educating patients about medications usually involves giving them written instructions and information and suggesting memory aids. However, many factors affect medication management, including the complexity of medication regimens and special instructions or actions required to take medications as prescribed. A recent study of epilepsy self-management found that self-efficacy and patient satisfaction had the greatest influence on medication-taking behaviors. Self-efficacy, social support, and locus of control have also been found to have important influences on quality of life for people with epilepsy. Nurses and other healthcare professionals must appreciate these complex relationships and consider strategies that can enhance a patient’s confidence, support, and satisfaction in managing medications and other aspects of epilepsy care.

Sometimes people with new-onset seizures are not seen by healthcare professionals frequently. Therefore, opportunities for teaching these patients may be sparse or infrequent. However, even brief moments that arise during office visits or phone calls can provide openings for validating concerns, disseminating correct information, or making referrals to professional or community resources for more in-depth information and support. The Internet can be another useful resource for learning; however, patients should be taught how to find and assess reliable and credible sources of information.

**Improving Quality of Life: The Nonmedical Issues**

Many factors outside the medical realm influence how well a person adapts to living with seizures. When seizures affect a person’s independence, ability to drive, or employment status, life can change dramatically. The ability of a patient to get to the doctor’s office, obtain healthcare insurance, or pay for needed medications or out-of-pocket expenses is often overestimated, yet this is becoming one of the most critical issues for people with chronic disorders such as epilepsy. Concerns regarding disclosure to friends, coworkers, and employers also arise. Some of these issues do not become apparent early in the course of epilepsy; if these concerns do arise, people may not discuss them with their doctors. Incorporating these areas into the routine care of people with seizures will help to identify concerns early, before refractory social problems develop. Referral to social workers, resource specialists, vocational rehabilitation counselors, and psychologists then should be offered as part of comprehensive epilepsy care.

**Conclusions**

Adults newly diagnosed with seizures may face innumerable challenges. The clinician’s goal is to optimize seizure control (ideally to achieve cessation of seizures and no side effects), but this will not necessarily ensure that patients will achieve optimal quality of life. Careful
attention to the many factors influencing seizures and medication management is critical, in addition to the recognition and treatment of comorbid conditions and psychosocial consequences. The nurse can play a central role in identifying these concerns, providing appropriate education and working with patients, their families, and other healthcare professionals to coordinate the necessary resources and supports.

REFERENCES


24. Pinto Richardson S, Farias ST, Lima AR 3rd, Alsaadi TM. Improvement in seizure control and quality of life in medically refractory epilepsy patients converted from polypharmacy to monotherapy. Epilepsy Behav. 2004;5:343-347.


