

HEALTH RELATED QUALITY OF LIFE AMONG PATIENTS WITH EPILEPSY: SUPPORT FOR A MODEL OF NURSING CARE

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Background. There are an estimated 2.32 million persons with epilepsy in the United States. Epilepsy is a chronic disorder of the central nervous system characterized by unprovoked, recurrent seizures. Medical care and research have focused on issues related to type, frequency and severity of seizures, medication effects, and surgical outcomes. While seizures are the most common physical symptom of epilepsy, the psychological and social domains are also affected, with reports of anxiety, depression, poor self-esteem, and problems with social involvement. It has been suggested that the psychosocial problems experienced by individuals with epilepsy are more handicapping than the seizures themselves. Thus, the traditional measure of success in treating epilepsy—reduced seizure count—does not capture the broad range of expected outcomes that providers in healthcare should be seeking.

Purpose. For the patient with epilepsy, visits to the physician tend to focus on medical issues, and psychosocial problems may not be raised due to lack of time or expertise. Nurses with special training can provide the advice and support needed by patients with epilepsy, a model used for patients with other chronic conditions such as diabetes. The purposes of the study were to: 1) evaluate the use of an epilepsy quality of life screening tool; 2) describe the findings from the screening instrument; and 3) determine essential nursing activities for an Epilepsy Care Protocol based on the findings.

Method. Patients (N=78) from a university hospital Epilepsy Care Program completed the Quality of Life in Epilepsy Inventory-89 (QOLIE-89). This 89-item instrument is a self-report quality of life measure for individuals with epilepsy. It contains 17 multi-item scales that tap various health concepts and has a reported internal consistency of 0.97. Demographic data collected included age, sex, race, educational level, marital status, employment, living situation, epilepsy drugs used, number of seizures in the last 3 months, and co-morbid conditions.

Findings: Results revealed a range of 0 to 180 seizures within the past three months among subjects, and a QOLIE-89 mean score of 54.8, well below the desired mean score of 68. Participants did not complain about the length of the QOLIE-89, and expressed appreciation for the interest in assessing quality of life issues. The subjects in this study had not experienced a comprehensive nursing-based Epilepsy Care Protocol. The results of the QOLIE assessment suggested there are a number of quality of life issues that would benefit from nursing interventions. The lowest subscales scores represented all four of the domain areas: Physical Health, Mental Health, Cognition, and Seizure-Specific Effects. For this subject cohort, there was a relationship between selected QOLIE subscales and gender, education, number of seizures, and marital status.

Discussion. The results suggested that a nursing protocol would greatly benefit patients with epilepsy. Such a protocol would likely address: 1) seizure safety and the seizure fear; 2) emotional well-being; 3) the short term and long term effects of anti-epileptic medications; and 4) community resources, support groups and advocacy programs that empower patients.

