Effects of an educational program on self-management in patients with epilepsy

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ABSTRACT

Purpose: Self-management majorly determines the health status of patients with epilepsy because the most important strategies for controlling seizures include receiving and adhering to prescribed therapies, and making appropriate lifestyle adjustments. Patients with epilepsy have various educational needs and must adopt many self-management behaviors to control their condition. This study was a clinical trial that evaluated the effects of an educational program on self-management in patients with epilepsy.
Methods: Participants ($n = 60$) were recruited from the Neurology Clinic in Zanjan, Iran. Patients were randomly assigned to the intervention and control groups ($n = 30$ in each). The intervention group received four educational sessions on epilepsy, including a self-management plan. All participants completed the Epilepsy Self-Management Scale before the intervention and 1 month post-intervention. The chi-square test, Fisher's exact test, independent *t*-test, and paired samples *t*-test were used to compare the groups.
Results: At baseline, demographic characteristics and self-management scores did not differ significantly. One month after the intervention, self-management scores differed significantly ($p < 0.001$) between the two groups.
Conclusion: The educational program had beneficial effects on self-management behaviors in patients with epilepsy.

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1. Introduction

Epilepsy is one of the most common chronic neurological conditions, secondary only to headache.[1] According to a report of the World Health Organization (WHO), approximately 50 million people worldwide have epilepsy.[2] The incidence is approximately 50–70 cases per 100,000 per year, excluding febrile seizures, which have a similar incidence. Age-specific incidence rates are highest in young children and the elderly and lowest in young and middle-aged adults. The lifetime prevalence is between 2% and 5% of the population.[3,4] Epilepsy is both a medical diagnosis and a social label that affects life physiologically, psychologically, and socially.[5] In fact, as a group, patients are affected more strongly by social and psychological aspects related to epilepsy than by seizures

themselves, and many studies indicate that patients with epilepsy have a lower annual income, a lower quality of life, poorer school performance, social stigma, and low self-esteem; thus, 75% of patients with epilepsy have serious adjustment problems.[6,7] There is a linear relationship between seizure severity and psychosocial problems. In addition, achieving full seizure control seems to be the most important factor in decreasing psychosocial problems. Based on the scope of the reported psychological and social problems associated with epilepsy (adjustment, self-image, unemployment, financial distress, insurance issues, and stigma), it is reasonable to conclude that this disease has a major impact on the patient, his or her family, and the society as a whole. Therefore, better seizure control is essential for patients with epilepsy and the society.[7] Traditional medical care of patients with epilepsy tends to focus on seizure control through drug treatment and surgical interventions.[8] Recently, it has been widely acknowledged that comprehensive epilepsy treatment goes far beyond medication.[9] In 1997, the Centers for Disease Control and Prevention (CDC-P) began crafting a public health agenda in this area, which culminated in the 2003 Living Well with Epilepsy II conference sponsored by the Epilepsy Foundation, CDC-P, and other epilepsy organizations. A number of priority recommendations resulting

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from this conference were directly related to self-management research in epilepsy.[10] Self-management in patients with epilepsy refers to adaptive health behaviors and activities that an individual can perform to promote seizure control and enhance well-being.[11] Kobau and Dilorio describe behavioral and psychosocial adjustments made by patients with epilepsy to control seizures and attain a higher quality of life. Behavioral adjustments include medication adherence, adequate sleep, good nutrition, and stress reduction. Coping with the loss of independence and dealing with embarrassment and stigma are psychosocial adjustments. All these adjustments comprise self-management behaviors.[12] Patients' diligence in adhering to their medication regimen as well as non-drug-related behavioral factors such as management of information, concern for personal safety, management of the seizures themselves and lifestyle issues play an important role in the overall success of epilepsy therapy.[13] The findings of previous studies on self-management in epilepsy indicate that self-efficacy is the primary determinant of general epilepsy self-management and that people with high self-efficacy levels are more successful at managing self-care tasks such as taking medications, avoiding triggers for symptoms, and monitoring health status.[14]

The need to manage chronic conditions and actively engage in a lifestyle that fosters health is increasingly recognized as the responsibility of an individual and his or her family. Health problems have shifted from acute to chronic, and personal behaviors are linked to over half of chronic health problems. Health care delivery has shifted to non-hospital venues with hospitalizations often eliminated or shortened. As nurses and other healthcare professionals, our expectations that individuals and families will assume responsibility for their health care management have outpaced our understanding of how to assist them in acquiring the knowledge, skills, and social support for health management. For individuals and families, management of chronic health conditions leads to better health outcomes, increased quality of life, and realignment of healthcare expenditures, including decreased demand for health services. Self-management also contributes to the overall health of society.[15]

Patient education is an important component of quality care and is considered to be a therapeutic outcome for patients with epilepsy.[16] Patients with epilepsy have various educational needs and must adopt many self-management behaviors to control their condition.[17] To increase self-management, patients need to have access to training and educational programs. In our country, patients with epilepsy are discharged from the hospital without any appropriate patient education, representing a significant problem with their treatment.

To the best of our knowledge, no studies have been conducted in Iran on self-management in patients with epilepsy. Therefore, this study evaluated the effects of an educational program on self-management in patients with epilepsy.

2. Methods

2.1. Procedures

A clinical trial was conducted at the Zanjan Hospital. The study was reviewed and approved by the appropriate ethics boards prior to initiation. Individuals were eligible to participate if they met the following inclusion criteria: they had a diagnosis of epilepsy for at least 1 year; they were receiving standard treatment for epilepsy, including antiepileptic drugs; they were aged between 18 and 70 years; they had experienced seizures during the previous year; they were able to understand and speak Persian; and they were willing to participate.

The participants in the intervention group received the usual level of epilepsy care and support offered by their clinic. They also received an intervention aimed at enhancing self-management practices. The participants in the intervention group were divided into six groups. Each group received a 1-month educational program comprising four 2-h sessions.

2.2. Delivery of the intervention

The intervention was delivered by a Master's student in nursing who had prior experience of working on a Brain-Neurology ward. The educational content was delivered in group sessions (4–6 patients in each group) in face-to-face lectures. The content was presented using PowerPoint slides, demonstrations, and case histories of patients facing the challenges of epilepsy. The same qualified professionals were responsible for teaching in every session. The educational content was divided into two parts. The first part, delivered during the first session, consisted primarily of education about the medical aspects of epilepsy, including the definition of epilepsy, a description of brain seizure activity, descriptions of the different types of seizures, seizure observation and classification, causes, and diagnostic procedures. In addition, during the first session, the intervention group received leaflets that contained the content of the educational program. The second part, delivered during the remaining three sessions, included self-management information in the following areas: medication, information, seizures, safety, and lifestyle education. A follow-up questionnaire was administered to the two groups one month after completion of the educational program. Both the groups completed the same questionnaire.

The participants in the control group received the usual epilepsy care and support offered by the clinic. As a control for attention, they received two brief courtesy telephone calls over the 1-month period during which the participants in the intervention group received the educational program.

2.3. Study measures

The participants completed the baseline assessment and a 1-month follow-up questionnaire. Demographic data including age, gender, marital status, occupation status, education, type of convulsions, attack frequency, the time since the last attack and the number of anti-epileptic drugs taken were collected from their medical records.

Epilepsy self-management was measured using the Epilepsy Self-Management Scale (ESMS).[14] We changed one question "I drink a lot of alcoholic beverages such as beer, wine, and whiskey". We deleted the reference to different types of alcoholic drinks because it seemed inappropriate in Iran where alcohol consumption is restricted for religious reasons. We changed original prompt to "I drink a lot of alcoholic beverages".

Each of the 38 items was rated on a 5-point Likert scale from "never" (1) to "always" (5). Higher total scores indicated more frequent use of self-management strategies. Possible scores ranged from 38 to 190. Participants scoring less than 50% of the highest possible score were categorized as "low", those scoring between 50% and 75% as "medium" and those above 75% as "high" users of self-management strategies. Cronbach's alpha for responses from the participants in this sample was 0.83.

2.4. Data analysis

The main variables of this study included the dependent variable of education and independent variable of self-management. To achieve our objectives, descriptive statistics were used for analyzing data and inferential statistics were used for comparing and finding relationships between variables.