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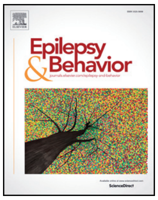

The effect of self-management training on health-related quality of life in patients with epilepsy

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ABSTRACT

Purpose: Epilepsy is the most common chronic neurological disease after headache. Health-related quality of life in patients with epilepsy is disturbed by psychosocial factors, seizures, and treatment side effects. This study was conducted to determine the effect of a self-management training program on quality of life in patients with epilepsy.

Methods: In this controlled clinical trial, 60 patients with epilepsy going to Zanjan Neurology Clinic were examined. The samples were selected using convenience sampling and divided randomly into the case group (30 people) and control group (30 people) using the table of random numbers. Four training sessions on the nature of epilepsy and self-managementwere run for the case group. All the patients completed an inventory for quality of life twice: before and one month after the intervention. The data were analyzed using the chi-square test, independent t-test, and paired t-test.

Results: There was no statistically significant difference between the two groups before the intervention in terms of personal specifications and scores and dimensions of the quality of life. One month after the intervention, a statistically significant difference was observed between the two groups in terms of the scores and dimensions of quality of life that indicated improved quality of life in the case group ($P < 0.001$).

Conclusion: The self-management training program improved the quality of life in patients with epilepsy. The present findings highlight that psychosocial variables can have incremental significance over biomedical variables in the health-related quality of life of patients with epilepsy.

1. Introduction

Epilepsy is a chronic neurological disease characterized by frequent seizures that vary in terms of frequency, severity, and prognosis [1]. It is the most common chronic neurological disease after headache, and 2–5% of people experience an epileptic seizure in their lifetime. The prevalence rate of epilepsy is 0.1–0.4%, and it is higher in developing countries than developed countries [2]. Epilepsy is not only a medical condition but also a social problem, and previous studies on quality of life in patients with epilepsy showed that patients were influenced by social and cultural negative effects, as well as frequent seizures [3–6].

The traditional treatment of epilepsy often emphasizes the medical aspects of epilepsy and control of seizures through medication therapy and pays little attention to the effects of epilepsy on patients' daily life, such as patients' perception of the disorder, coping with the disease and its treatment, and ability to treat complications of epilepsy, although the psychosocial problems of epilepsy may be more disruptive than its physical symptoms for patients [3].

Epilepsy influences many dimensions of quality of life [7,8]. Studies showed that patients with epilepsy experienced lower quality of life than normal people [9,10], and quality of life in patients with epilepsy was even lower than that in patients with other chronic diseases [11]. Epilepsy presents an identity of exclusion, which, at multiple levels, hinders the ability to engage with one's community [12]. The important factors influencing the quality of life of patients with epilepsy include behavioral, mental, and cognitive conditions; the ability to work; social functioning; family stability; self-esteem; social stigma; and coping with the disease. Even if seizures are controlled, psychosocial problems and the effects of antiepileptic drugs largely affect patients' quality of life [13]. While is a correlation between a patient’s knowledge about

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epilepsy and their ability to cope with the disease; studies suggest that patient knowledge about epilepsy is generally limited [14].

Numerous training programs have been developed for providing comprehensive care to patients with epilepsy [15]. Several training programs have been developed for patients with epilepsy in Iran, and studies showed their effectiveness on self-management and patients' satisfaction but not on their quality of life. Furthermore, conventional studies on pathogenicity, mortality, and life expectancy are not sufficient for health assessments any longer, and consequently, quality of life has received more attention in recent assessments of health-care services. Today, the improvement of the quality of life of patients with chronic epilepsy is facilitated by specific questionnaires that have been developed for evaluating their quality of life [16,17]. Many of those questionnaires have been translated into Persian. However, most of the studies on quality of life were performed in western countries, and the information about quality of life in eastern and developing countries is limited to descriptive studies. A study conducted in Taiwan reported low quality of life in patients with epilepsy in some dimensions including physical and psychosocial dimensions, independence, and social relations [1]. Moreover, an extensive study performed in Iran and Persian Gulf countries (Bahrain, Kuwait, Oman, Qatar, Cyprus, Jordan, Lebanon, Syria, and the United Arabic Emirates) revealed that patients with epilepsy had low quality of life in dimensions such as physical and social dimensions and energy [7]. Given that previous studies showed low quality of life in patients with epilepsy and few studies were performed to improve quality of life, the researchers conducted this study to determine the effect of a self-management training program on quality of life in patients with epilepsy.

2. Methods

In this controlled clinical trial conducted in a teaching hospital in Zanjan, Iran, 60 patients with epilepsy were selected using simple random sampling and divided randomly into the case group (30 people) and the control group (30 people) using the table of random numbers. We calculated the sample size based on the study conducted by Pramuka et al. [18] on patients with epilepsy and using $\alpha = 0.05$ and power = 80%. The mean QOL of that study using QOLIE-31-P (see below) was 67.3 ± 2.6 in the case group and 65 ± 2.8 in the control group. The sample size was calculated as 30 in each group [18].

The inclusion criteria of the study were as follows: age between 18 and 65 years, suffering epilepsy for at least 1 year; using antiepileptic drugs experience of at least one seizure during the last year, ability to read and write, and willingness to participate in the study. The exclusion criteria were as follows: presence of conditions in which patients need intensive care, participation in other studies, and absence from each training session.

The study setting was an educational medical center selected in order to have easy access to patients with epilepsy, abundance of samples, easy data collection, and an appropriate educational environment.

The data were collected using a demographic information form and the standardized inventory for QOL in patients with epilepsy (QOLIE-31-P). The inventory contains 31 items measuring 7 dimensions of QOL and one general item examining the importance of the dimensions related to the disease. The dimensions of the inventory are as follows: seizure worry, mental health, energy/fatigue, cognitive functioning, medication effects, social functioning, and the overall QOL. The score of each scale is measured according to the scoring guide of the inventory. The scores range from 0–100, with higher scores indicating higher QOL. The reliability and validity of this scale have already been evaluated in Iran, and the reliability of most of the dimensions is confirmed [19]. To respect ethics, a written permit was adopted from the translator of the inventory. The training materials consisted of two parts. The first part that was provided in the first session was about the medical aspects of epilepsy including the definition of epilepsy, description of seizures, types of seizures, observation and classification of its causes, and diagnosis of epilepsy. Moreover, the case group received an epilepsy instructional booklet containing the content of the training program. The second part that was provided within three sessions for promoting self-management was about medication management, information management, safety management, lifestyle management, and seizure management. The materials were presented face-to-face using PowerPoint presentations. These materials were already prepared by Aliasgharpour et al., its face validity on 15 patients with epilepsy had been confirmed, and it had been examined and revised in terms of readability, fluency, and understandability. Their study showed that the training had significant effects on the self-management of patients with epilepsy [20]. The patients in the case group received both the routine care and the training intervention for improvement of self-management. To do so, they were divided into 5 groups (5–6 patients in each group) and received the training intervention within four 2-hour sessions in one month. We phoned the entire group before every session to encourage them to attend. The participants completed the inventory for QOL (QOLIE-31-P) before and one month after the intervention. The control group received only the routine clinical care and was contacted only through two short phone calls during the month. The case group received the intervention. All of the participants in the two groups completed the study. The groups filled out the posttest when they referred to the center for their treatment.

2.1. Data analysis procedures

The main variables of this study were the independent variable of self-management training and dependent variable of quality of life. To obtain the objectives, the data were analyzed with descriptive statistics, and comparison of variables and finding their correlations were done using inferential statistics. Therefore, the chi-square test was used to compare the two groups in terms of the demographic characteristics, the paired t-test was used to measure quality of life in each group (before and after the intervention), and the independent t-test was used to compare the quality of life of the two groups at the same time. The statistical analysis of the data was performed using the SPSS16 software.

3. Results

The 60 patients with epilepsy were randomly divided into the case group (30 patients) and control group (30 patients). The results showed that of the participants, 61.7% were 18–25 years old, 51.7% were male, 61.7% were single, 41.7% were working, and 55% did not have a high school diploma. Moreover, of the participants, 95% had generalized seizures, 58.3% experienced seizures during the last month, 45% experienced one seizure during the last year, and 71.7% used one drug to control seizures. The patients in the two groups did not have any significant differences in terms of all demographic specifications and disease symptoms (Table 1).

The results of the independent t-test before the intervention did not show any significant difference in the case and control groups for the total quality of life ($t = 0.772$, $df = 58$, $p = 0.444$) and dimensions of quality of life: overall quality of life ($t = 0.679$, $df = 58$, $p = 0.500$); social functioning ($t = 1.23$, $df = 58$, $p = 0.221$); medication effects ($t = 0.424$, $df = 58$, $p = 0.673$); cognitive functioning ($t = 0.185$, $df = 58$, $p = 0.854$); energy/fatigue ($t = 1.258$, $df = 58$, $p = 0.214$); mental health ($t = 0.644$, $df = 58$, $p = 0.522$); and worry about seizures ($t = 0.343$, $df = 58$, $p = 0.733$). In other words, the two groups were matched in terms of the total quality of life and its dimensions. However, the results of the independent t-test after the intervention revealed a significant difference in the case and control groups for the total quality of life ($t = 5.22$, $df = 58$, $p < 0.001$) and dimensions of quality of life: overall quality of life ($t = 5.47$, $df = 58$, $p = 0.004$); social functioning ($t = 2.11$, $df = 58$, $p = 0.039$); medication effects ($t = 7.004$, $df = 58$, $p < 0.001$); cognitive functioning ($t = 2.54$, $df = 58$, $p = 0.014$); energy/fatigue ($t = 5.54$, $df = 58$,