



Effects of family-centered empowerment intervention on stress, anxiety, and depression among family caregivers of patients with epilepsy



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ABSTRACT

Objectives: Family caregivers face numerous challenges in taking care of their family members with epilepsy. The empowerment of this group of people, who can be described as forgotten patients, should always be considered through supportive interventions; therefore, this study investigated the effect of a family-centered intervention program on stress, anxiety, and depression among family caregivers of patients with epilepsy.

Methods: In 2017, a trial was conducted in Iran among subjects selected by the convenience sampling method and randomly assigned to two groups: intervention and control. After five sessions per week over a four-week period, the intervention- and control-group data were collected using the Depression Anxiety Stress Scale (DASS) in three stages: before, immediately after, and two months after the intervention. Data were analyzed with Statistical Package for the Social Sciences (SPSS) software using descriptive and analytical statistics, an independent *t*-test, and repeated measures Analysis of variance (ANOVA).

Results: In this study, the family caregivers included 61.3% women and 38.7% men, with a mean age of 37.5 years. The findings showed no significant differences in the mean scores of stress ($p = 0.93$), anxiety ($p = 0.91$), and depression ($p = 0.56$) before the interventional program between the intervention and control groups, but these differences were statistically significant in the mean score of stress ($p = 0.003$) in the immediately after the interventional program, whereas the mean scores of depression were not decreased significantly ($p = 0.3$). Two months after the interventional program the mean scores of stress ($p = 0.001$) and anxiety ($p = 0.001$) were significantly decreased in the intervention group, but the mean score of depression was not decreased significantly ($p = 0.09$).

Conclusion: The results suggested that a family-centered intervention program reduced the stress, anxiety, and depression of caregivers because of feasibility, simplicity, and utility of intervention. This program was focused on psychological issues of caregivers, and an emphasis on their empowerment helped them in managing their problems in the caregiving situation and achieved greater psychological potency in the caring process.

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1. Introduction

Epilepsy is one of the most common neurological disorders [1]. Through transient and recurrent impairment in brain electrical function [2], epilepsy leads to seizures [3]. Research indicates that there are 65 million patients with epilepsy throughout the world [4]. The overall incidence of epilepsy has been reported to be 5% in Iran [5].

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Epilepsy affects not only the person with the disorder but also all family members [6]. The occurrence of a chronic disease in a family member is a critical occurrence for the entire family [7]. Epilepsy often comes with social, cognitive, emotional, and physical challenges that can have negative effects on family dynamics and reduce quality of life for both caregivers and the patient [8]. In the context of healthcare in Iran, providing care for a person with chronic illness can create tremendous stress for the caregiver and the family of the patient. The caregivers of patients with epilepsy are often parents, spouses, family members, or friends of the patient, and they are often referred to as “forgotten patients” because they experience emotional problems such as anxiety, depression, loneliness, frustration, anger, isolation, fear, and concerns about care [9]. A literature review revealed that the presence of epilepsy in the family causes mental disorders and negative changes in family dynamics, in which the family of a person with epilepsy experiences a significant level of stress – and is vulnerable to stress because the

biological, social, and psychological demands of the patient take precedence over their own needs [10–12]. Studies have shown that about 50% of mothers with children with epilepsy are prone to depression and anxiety; the consequences of epilepsy and the occurrence of mental disorders, including anxiety, create a significant emotional burden for caregivers [13]. In addition, there is misinformation about and a poor understanding of epilepsy in Iranian care settings, which result in significant stress for both patients with epilepsy and their families [14].

Iranian caregivers' understanding of epilepsy is generally poor and inaccurate, and this is linked to a reduction in their general health [15]. During patient care, the family needs a proper understanding of the disease, and along with patient care, it is the responsibility of the healthcare and treatment staff to help the family increase its hope and confidence [16].

As a result of advances made in addressing health problems in Iran, family caregivers have been replaced by healthcare centers [17]. Iranian nurses are also in a unique position to interact with individuals and family members [18] so that they can provide the necessary knowledge, skills, and support caregivers need in order to maintain quality of care at home [19]. However, family caregivers need more and better access to appropriate resources, such as knowledge, to improve their understanding of caregiving and assistance of their family members, better self-management skills to strengthen their self-efficacy levels for better adaptation [20], and most importantly, the support of doctors, nurses, rehabilitation experts, and social workers.

The family has a vital role in supporting the patient through a chronic illness. When family members' needs are not attended to or met, significant conflict occurs. Family-centered care focuses on the whole patient as a member of a family unit. It incorporates the family as a team member in the healing process. Family-centered care is a collaborative approach to care and not a unilateral approach on the part of the clinicians or the family.

The philosophies of family-centered care are appreciating families as families and individuals as individuals, recognizing that they possess a wide range of strengths, concerns, emotions, and aspiration beyond their need for specialized health services and support. Also, ensuring that hospital, home, and community service and support systems for individuals and their families needing specialized health and development care are flexible, accessible, and comprehensive in responding to diverse family-identified needs. The other aspects of family-centered care benefits are facilitating family/professional collaboration at all levels of hospitals, home, and community care and enhancing complete and unbiased information between families and professionals in a supportive atmosphere at all times [21].

The dominant conceptual model for caregiving assumes that the onset and progression of chronic illness and physical disability are stressful for both the patient and the caregiver. Therefore, the framework of family-centered empowerment model can be used to study caregiving. Within this framework, objective stressors include the patient's physical disabilities, self-concept impairment, and problem behaviors, as well as the type and intensity of care provided. In caregivers, these objective stressors lead to psychological stress, state and trait anxiety, and situational depression due to overwhelming tasks in caring situation.

Literature review in this area showed that psychological aspects of caregiver challenges in chronic diseases such as stress, anxiety, and depression were the most important issues for family caregivers [22–24].

Family-centered care in Iran based on the Rabiei et al. [25] study is the best way to recognize the needs of the families as well as their physical and psychological problems. In this caring model, caregivers and other members of the health team try to provide care programs for all family members as caregivers so that family involvement in planning, decision-making, and provision of special care can transform patient-centered care programs into patient-and-family-centered care programs. Studies have shown that family involvement in care programs is an effective factor in acquiring care capabilities, making decisions, and feeling more responsible for the patient [26]. The present study

seeks to contribute to the limited research on family-centered care for patients with epilepsy.

2. Methods

The current field trial was conducted in the Neurology Department of Ayatollah Kashani Hospital at Shahrekord University of Medical Sciences in 2017. To qualify for inclusion in the study, family caregivers of patients with epilepsy had to satisfy the following criteria: qualification for care of patients with epilepsy, such as being a family member with the primary responsibility of providing daily care for the patient, provision of daily care for at least 8 h per day, living with the patient, and over the age of 18 years, no previous participation in family education sessions (i.e., any other research project), and no history of severe physical illnesses or known psychiatric disorders.

The caregivers of patients with epilepsy were recruited from Imam Ali Clinic, Hajar and Kashani Hospitals of Shahrekord University of Medical Sciences, and Shahrekord Epilepsy Association via community advertising. The mean age of the patients with epilepsy was 31 years. The grand mal seizure was the most common type, and temporal lobe, partial, and focal absence seizures were also reported. Most of the patients with epilepsy had at least two seizures in the previous year (72%), and 28% of them experienced a convulsive seizure in the previous year. Most of the patients with epilepsy had seizures that lasted less than 4 min on average.

Carbamazepine was the most frequently prescribed drug (69%), followed by sodium valproate (31%), topiramate (28%), lamotrigine (21%), phenytoin (18%), and clonazepam (14%). Of the patients, 73% took the medication twice daily and 27% did so three times daily.

In this study, the sample size was determined to be 50 subjects in each group and 100 total according to similar studies, statistical formulas, 95% confidence interval, and 80% test power. Finally, the sample size was estimated to be 50 in each group, taking dropouts into account. The samples were selected using the convenience sampling method and then assigned randomly to control and intervention groups using a random number table (Fig. 1). Data were collected using the Depression Anxiety Stress Scale (DASS), which consists of two sections: demographic characteristics of the caregiver and the short-form version of the DASS. The shortened version of the DASS 21-item version has been used in several studies because its items can easily be responded to. The items are responded to using a 4-point scale (never: 0, to some extent: 1, to a large extent: 2, and very often: 4). The range of scores is 0–21 for each domain (anxiety, stress, and depression) and therefore, 0–63 for the total scale. The mean scores 0–21, 22–43, and 44–63 represent mild, moderate, and severe levels of anxiety, stress, and depression, respectively [23,27,28].

A study by Khayeri et al. confirmed the reliability of the DASS 21-item version using Pearson's correlation coefficient and reported 0.79, respectively [29].

After the caregivers provided informed written consent in accordance with the guidelines of the committee on human research, they completed a pretest. Subsequently, after random allocation of samples to the intervention and control groups, the intervention group was invited to participate in a family-centered care program. The control group received only routine interventions.

The intervention program was underpinned on the four steps of the family-centered empowerment programs of Rabiei et al.'s [25] study at Iranian context that included: increased perceived threats, enhanced self-efficacy, promoted self-esteem, and evaluation. The packaged supportive-educative program consisted of five sessions per week over a four-week period and was presented by a research team (neurologist, psychiatric nurse, neurology nurses) during educational and support sessions through lectures, group discussions, and a question-and-answer period. The scientific materials are about caregivers' knowledge and skills on disease management, sensitization of realistic expectations regarding prognosis and treatment of the disease, knowledge and skills about drug therapy, improving preparedness for patient care, ability to enhance

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