

Evidence Based Care Journal

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The online version of this article can be found at
http://ebcj.mums.ac.ir/article_14043.html

Evidence Based Care Journal 2019 09:41 originally published
online 01 October 2019
DOI: 10.22038/EBCJ.2019.14043

Online ISSN: 2008-370X

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Effect of Implementing Family-Centered Empowerment Model on Burden of Care in Caregivers of the Elderly with Parkinson's Disease

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Received: 14/07/2019

Evidence Based Care Journal, 9 (3): 41-48

Accepted: 13/10/2019

Abstract

Background: Caring for a patient with Parkinson's disease (PD) imposes a high burden of care on caregivers due to its chronic and progressive nature. Implementation of an empowerment program leads to self-control and adoption of preventive behaviors.

Aim: This study investigated the effect of a family-centered empowerment model on the burden of care among the caregivers of the elderly with PD.

Method: The present randomized controlled clinical trial was performed on 60 caregivers and elderly people with PD referring to the Neurology Clinic of one of the two large hospitals of Mashhad, northeast Iran, in 2018. In the intervention group, the family-centered empowerment model consisted of four steps, including perceived threat, problem-solving, educational participation, and evaluation, in four training sessions. Before and 1.5 months after the training sessions, both groups completed the Zarit Burden Interview questionnaire. The control group also received routine care. The data were analyzed by SPSS software (version 16) using paired t-test, independent t-test, Wilcoxon test, and Mann-Whitney U test.

Results: The two groups were homogeneous regarding demographic findings. The difference in pre and postcare burden scores decreased 25.1 ± 13.9 and 0.6 ± 3.1 in the intervention and control groups, respectively. Independent t-test showed a significant difference ($P < 0.001$). Intragroup comparison by paired t-test in the intervention group showed a significant difference between the total care burden score before and after the intervention ($P < 0.001$).

Implications for Practice: Using the empowerment model focusing on the management of care programs leads to reducing the burden of care and improving the role of caregivers. Therefore, it is recommended to implement family-centered empowerment programs for the caregivers of patients with chronic diseases.

Keywords: Burden of care, Caregivers, Elderly, Family-Centered empowerment model, Parkinson's disease

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Introduction

Phenomenon of global aging has become one of the most important public health challenges in recent years (1, 2). Number of elderly people in the world is increasing. However, only 13% of the world's population were over 60 years old in 2000, the proportion is projected to reach 20% by 2040. According to the census of Iran in 2016, people over 60 years of age accounted for about 9.3% of the Iranian population (3, 4).

Population aging leads to increased supportive social rehabilitation problems, especially health concerns. According to the World Health Organization, the proportion of elderly people using health services is higher than the general population. Among these, chronic diseases have accounted for a significant share (5). Parkinson's disease (PD) is one of the chronic diseases that is an age-related condition whose prevalence increases with age. It is a type of degenerative disorder of the central nervous system and the second most common neurodegenerative disorder after Alzheimer's disease. The disease is very common among the elderly, and its prevalence increases from 1% in people over 60 to 4% in people over 80 years of age (6).

Progressive nature of extensive, physical, psychological, and social disorders and lack of definitive treatment for PD can sometimes impose huge costs on patients. In addition to direct economic costs, the indirect costs of treating and controlling the disease cannot be overlooked. One of the most important issues regarding this disease is the involvement of at least one family member in patient care. Indirect costs of this disease are very high for caregivers due to the reduced function and burden of the disease (7). Elderly people with chronic illnesses, such as PD, not only affect themselves but also family members, friends, and others as caregivers may somehow be involved (8).

Naturally, caregivers have different and limited abilities in meeting their elderly patient's needs, making caregivers vulnerable to changes in the caring needs of the patients at home (9). Increasing the burden of care on the caregivers of the elderly will have risky consequences for the family, such as depression and anxiety. Since the caregivers are considered a group physically, mentally, and financially vulnerable, it is undoubtedly essential to support family caregivers (10). The family, as the most basic pillar of society, is responsible for providing correct healthcare for patients and their relatives. In caring for a patient, the family needs a proper understanding of the disease and the nurse's duty, along with the patient's care, that helps the family increase hope and confidence. Consequently, such an approach will promote family health and well-being (10, 11).

The family-centered empowerment model is one of the most effective educational strategies for the caregivers of chronic patients. This model has been designed to emphasize the effectiveness of the family's role in motivational, psychological, and knowledge dimensions, as well as perceived attitudes and threats. Inadequate knowledge and skills reduce the motivation for the adoption of preventive measures and as a result develop a defective cycle that results in inadequate prevention. Therefore, it is necessary to implement an empowerment program aimed at increasing awareness, knowledge, and self-efficacy leading to behavioral self-control and adopting preventive behaviors to promote health and improve the quality of life (12, 13).

Despite performing diverse national studies on PD patients, there have been no studies focusing on using a comprehensive program that can address all the aspects and problems of caregivers as a backbone of patient support-care. Families shoulder the most burden of care in chronic diseases and health problems. Therefore, caregivers are of particular importance and support their clients. Programs that focus on the performance of the caregivers of the elderly with a family-centered and effective approach are important and should be considered. Therefore, the present study aimed to determine the effect of family-centered empowerment model on the burden of care in caregivers of elderly patients with PD.

Methods

The present randomized controlled trial with a pre/posttest design started after obtaining a clinical trial code and approval from the University Ethics Committee, receiving formal authorities from the School of Nursing and Midwifery in Mashhad University of Medical Sciences, and introducing them to the special Neurology Clinic of Ghaem Hospital in Mashhad, Iran, and obtaining permission from that center. The target population was the main caregivers and the elderly with PD referred to the Neurology Clinic at Ghaem Hospital in Mashhad.

The final sample size was determined with reference to the rates of type I and type II errors based

on the results of a study by Bagherbeik Tabrizi et al. in 2015 (14). Mean values of the burden of care were 39.5 ± 5.88 and 8.44 ± 5.87 in the intervention and control groups, respectively. The minimum sample size was estimated to be 29 in each group using the formula for comparing the means of two populations with 95% confidence interval and 80% test power. Finally, 32 individuals in each group were enrolled in the present study. In the intervention group, two patients were excluded due to their absence. In the control group, two subjects were also excluded due to incomplete questionnaires.

The inclusion criteria were caregivers as family members and main caregiver for the elderly, patient care for at least 6 months, literacy, and elderly aged over 60 years, definitive diagnosis of PD, and absence of other major illnesses, such as malignancies. The exclusion criteria were the death of a patient or involvement with another illness, occurrence of conditions in which the caregiver cannot make use of the provided training, absenteeism for more than one training session, and sending the elderly to the nursing home.

The data collection tools were demographic information and Zarit Burden Interview (ZBI) questionnaires. The demographic information questionnaire consisted of 10 items the validity of which was determined using content validity. The ZBI questionnaire was developed by Zarit et al. in 1998 to measure the burden of care. The questionnaire consisted of 22 items in four individual, social, emotional, and economic dimensions. The questionnaire was translated by Navidian et al. (2010) according to the Iranian cultural conditions, whose reliability was reported to be 94% (15). The questionnaire validity was confirmed by positive and high correlation with Hamilton Anxiety Rating Scale ($r=89\%$) and Beck Depression Inventory ($r=+67\%$). Reliability coefficient of the original version was 71% by the test-retest method, and the internal consistency using Cronbach's alpha coefficient was 91%. Reliability of the tool in this study was 90% using Cronbach's alpha coefficient.

The convenience sampling was performed by identifying the caregivers of the elderly with PD referred to the Neurology Clinic of Ghaem Hospital. After introducing the researcher to the caregivers, the study objectives were described to them. Main caregivers and selected elderly patients were randomly assigned to either the control or intervention group. The participants were asked to choose one of the two sheets on which the words "intervention and control" were written and throw it into a box.

The elderly were assigned to the control or intervention group according to the words written on the selection sheet. The ZBI questionnaire was also completed by the participants. The introduction session was designed for the test group to assess the needs and then determine educational content. The family-centered empowerment model program included four 45-minute sessions held two sessions per week for 2 weeks in the Nursing School in the presence of the caregiver and the elderly in the following three stages:

A) Pre-intervention

Initially, a two-hour session was held to determine the needs, problems, and limitations of care in the intervention group. In this session, important educational problems and requirements were identified for the caregivers, including the symptoms and complications of the disease, proper nutrition, medications and the effects, as well as motor skills. Based on these needs, training packages (i.e., pamphlets and training cards) were developed by the researcher according to the literature and consulting with neurologists.

B) Intervention

Contents of the training sessions were tailored to the requirements and desires of the participants. In the intervention group, the family-centered empowerment model was implemented for the caregivers and the elderly based on the model steps as a group discussion in three 10-person groups in four 45-minute sessions 2 days a week for 2 weeks.

Step One (Perceived Threat)

This phase was performed for the caregivers and the elderly in two 45-minute sessions by the researcher using lecture and group discussion, with the aim of increasing knowledge and cognition and as a result understanding the perceived threat through the awareness of the nature and late

complications of PD and important issues regarding nutrition, exercise, and other factors controlling the disease.

Step Two (Problem-Solving)

This phase was performed using a group-discussion method consisting of the main caregiver and the elderly in two 45-minute sessions. People also relied on their experiences to better control the disease and identify the problems and problem-solving process, suggested solutions, and then chose the best one for the better management of the problem.

Step Three (Educational Participation)

The participants were asked to deliver the material discussed in previous sessions by the patients and caregivers to other family members. In class, the individuals also exchanged ideas about what was presented. At the end of the sessions, the main caregiver and patient were provided with a researcher-made pamphlet approved by a neurologist.

Step Four (Evaluation)

During the intervention process, learning the content of previous sessions was evaluated by asking oral questions about the illness and care learned in the training classes.

C) Post-intervention

The final evaluation was immediately repeated after the intervention for the intervention group and 1.5 months after the last empowerment session for the intervention and control groups. During this time, the researcher communicated with the caregivers through telephone to resolve the problem, and the ZBI questionnaire was also completed at this stage.

Informed consent was also obtained from the participants. They were explained about the confidentiality of the collected information and voluntary participation in the study. Ethically, all educational issues related to empowerment sessions were pamphleted and instructed to the control group. The data were analyzed by SPSS software (version 16). Descriptive statistics included frequency distribution, as well as mean and standard deviation.

In analytical statistics, the normality of quantitative variables was firstly assessed using Kolmogorov-Smirnov and Shapiro-Wilk tests. To assess and compare the two groups in terms of homogeneity, independent t-test was used for quantitative variables with normal distribution, Mann-Whitney U test for those with nonnormal distribution, as well as Chi-squared test and Fisher's exact test for qualitative variables. To test the research hypotheses, independent t-test was employed for intergroup comparison, and Mann-Whitney U test was performed for nonnormal distribution. P-value less than 0.05 was considered statistically significant.

Results

Mean values of caregivers' age were 50.6 ± 13.1 and 46.4 ± 13.8 years in the intervention and control groups, respectively. Moreover, 83.3% ($n=25$) and 96.7% ($n=29$) of the caregivers in the intervention and control groups were married, respectively. There were no statistically significant differences in demographic variables, age, gender, educational level, and marital status between the intervention and control groups, and the two groups were homogeneous in this regard (Table 1).

Total mean scores of the burden of care before the intervention were 54.6 ± 23.2 and 64.1 ± 12.7 in the intervention and control groups, respectively. In this regard, independent t-test showed no significant difference ($P=0.55$). Total mean scores of the burden of care after the intervention were 29.5 ± 0.14 and 63.5 ± 11.8 in the intervention and control groups, respectively. Results of the Mann-Whitney U test showed a significant difference in this regard ($P<0.001$). The difference in the burden of pre and postcare scores decreased 25.1 ± 13.9 and 0.6 ± 3.1 in the intervention and control groups, respectively. The independent t-test showed a significant difference in this regard ($P<0.001$). The intragroup comparison by paired t-test in the intervention group showed a significant difference in the total burden of care score after the intervention ($P<0.001$). Wilcoxon test in control group indicated no significant difference in total burden of care score after the intervention (Table 2; $P=0.338$).

Table 1. Comparison of demographic characteristics of caregivers of the elderly with Parkinson's disease between intervention and control groups

Variables	Groups		Test results
	Intervention (n=30)	Control (n=30)	
Number of children	2.4±2.1	2.2±1.9	P=0.667*
Mean±standard deviation	50.6±13.1	46.4±13.8	P=0.198*
Educational level Frequency (percentage)	Uneducated	4 (13.3)	5 (16.7)
	High school	14 (46.7)	14 (46.7)
	Associate's Degree	4 (13.3)	2 (6.7)
	Bachelor's degree	8 (26.7)	9 (30.0)
	Total	30 (100.0)	30 (100.0)
Occupational status Frequency (percentage)	Retired	7 (23.3)	3 (10.0)
	Employed	12 (40.0)	16 (53.3)
	Housekeeper	11 (36.7)	11 (36.7)
	Total	30 (100.0)	30 (100.0)
	Female	19 (63.3)	19 (63.3)
Gender Frequency (percentage)	Male	11 (36.7)	11 (36.7)
	Total	30 (100.0)	30 (100.0)
	Single	5 (16.7)	1 (3.3)
Marital status Frequency (percentage)	Married	25 (83.3)	29 (96.7)
	Total	30 (100.0)	30 (100.0)

* Mann-Whitney U test

** Chi-squared test

*** Mann-Whitney U test

**** Fisher's exact test

Table 2. Total mean scores of the burden of care in caregivers of elderly patients with Parkinson's disease before and after intervention in intervention and control groups

Total scores of burden of care	Groups		Intergroup test results
	Intervention (n=30)	Intervention (n=30)	
	Mean±standard deviation	Mean±standard deviation	
Pre-intervention	54.6±23.2	64.1±12.7	P=0.055*
Post-intervention	29.5±14.0	63.5±11.8	P<0.001**
Differences between pre- and post-interventions	-25.1±13.9	-0.6±3.1	P<0.001*
Results	P<0.001***	P=0.338****	

* Student's t-test

** Mann-Whitney U test

*** Paired t-test

**** Wilcoxon test

Table 3. Mean scores of different dimensions of burden of care in caregivers of elderly patients with Parkinson's disease before and after intervention in intervention and control groups

Variables	Groups		Intergroup test results
	Intervention (n=30) Mean±standard deviation	Control (n=30) Mean±standard deviation	
Individual dimension of burden of care	Pre-intervention	22.6±9.2	26.5±5.6
	Post-intervention	11.6±6.2	26.0±5.5
	Differences between pre-and post-intervention	-11.0±5.8	-0.5±1.8
	Intragroup test results	P<0.001*	P>0.165*
Social dimension of burden of care	Pre-intervention	9.3±4.7	11.7±2.3
	Post-intervention	5.1±2.7	11.3±2.3
	Differences between pre- and post-intervention	-4.2±3.0	-0.4±1.0
	Intragroup test results	P<0.001*	P=0.043*

Table 3 Continued.

Emotional dimension of burden of care	Pre-intervention	17.8±7.7	20.1±4.2	P=0.818
	Post-intervention	9.9±4.7	20.3±4.1	P<0.001
	Differences between pre- and post-intervention	-7.9±4.5	0.1±1.9	P<0.001
	Intragroup test results	P<0.001**	P=0.657**	
Economic dimension of burden of care	Pre-intervention	4.9±2.5	5.8±1.7	P=0.218
	Post-intervention	2.9±1.8	6.0±1.6	P<0.001
	Differences between pre- and post-intervention	-2.0±1.8	0.1±1.1	P<0.001
	Intragroup test results	P<0.001**	P=0.509**	

* Paired t-test

** Wilcoxon test

Discussion

The obtained results demonstrated that the use of the family-centered empowerment model for the main caregiver can reduce the burden of care among the caregivers of the elderly with PD. The observed changes are important because these caregivers are confronted with the phenomenon of caring for clients who are suffering from chronic, progressive, and overwhelming illnesses that increases their burden with increasing the severity of the disease.

Wressle et al. (2007) investigated the perspectives of elderly patients with PD and their caregivers in their daily lives. In this regard, the results showed that PD affects not only the patient but also their relatives causing problems in their daily actions and social relationships, such as decreased social relationships and anxiety (16). Accordingly, studies have suggested that interventions, such as education and family therapy, should be used to reduce the extent of pressures on caregivers to improve both the quality of patient care, as well as physical and mental health of caregivers as hidden patients (15).

In a study carried out by Siu-Ching LO (2006), the voluntary empowerment of older people was examined in Hong Kong. It was observed that family-centered care should lead to support services for seniors over 60 years of age and their caregivers in mental, participatory, knowledge, and cognitive domains in order to improve their quality of life. Moreover, family-centered care should promote self-esteem and encourage productive and effective activities in the community (17). Findings of the aforementioned study are in line with the results of the present study indicating that the implementation of family-centered programs has a positive impact.

Navidian et al. (2010) in their study on the caregivers of psychiatric patients showed that the group intervention program reduced the psychological burden on the home caregivers of patients. In addition, group intervention programs could also improve and enhance the quality of life of patients and caregivers (18). In another study, Bagherbeik et al. (2015) studied the effect of cognitive-behavioral intervention on the burden of family caregivers of patients with Alzheimer's disease. It was indicated that there was a significant difference in the mean burden of care between the experimental and control groups after behavioral-cognitive interventions (14).

Masoudi et al. (2010) investigated the effect of the family-centered empowerment model on skill, attitude, and knowledge of multiple sclerosis (MS) caregivers and exhibited that the empowerment of MS caregivers improves their role performance (19). Results of these studies are in line with the findings of the present study because performing a family-based educational intervention leads to increased awareness, perception, and skill of caregivers in caregiving and facilitates care for caregivers due to overlooking all aspects and problems related to the disease and training in applied care skills.

Based on the results of the present study and aforementioned studies, it was observed that the family-centered empowerment model can strengthen the family, as the fundamental axis of care, to endure the burden of care by focusing on increasing knowledge and awareness and managing problem-solving in confronting with the problems of chronic patients. In so doing, the mental, psychological, physical, and economic impacts of caring for them can be tolerated through participatory planning. There were some limitations in the present study, including the differences in the learning level of families and transferring their education to elderly patients.

Implications for Practice

Family caregivers of patients with chronic illnesses, as people at risk of the disease, under the name of hidden disease, are under great burden. Interventions, such as the implementation of an empowerment model with regard to educational and therapeutic needs, will help them to change their attitudes about the disease symptoms, as well as behavioral signs and symptoms, reduce their severity of stress and mental and physical strain, and promote their quality of life and self-efficacy. Findings of the present study indicated the effectiveness of the family-centered empowerment model training on reducing the burden of care among the caregivers. Such interventions with respect to their efficacy, low cost, and safety, while also being effective, can help family caregivers of patients, especially the individuals with chronic illnesses such as PD, to increase their quality of special care and decrease their burden of care.

Acknowledgments

The present article was extracted from an MSc thesis in Geriatric Nursing and a research project approved by Mashhad University of Medical Sciences (code: 970282) and registered in the Iranian Registry of Clinical Trials (IRCT20181014041342N1). The authors would like to thank and appreciate the Deputy of Research at Mashhad University of Medical Sciences for financial support, all caregivers and patients with PD, and Dr Ali Shoeibi.

Conflicts of Interest

The authors declare that there is no conflict of interest.

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