



The effect of self-care education on quality of life of Parkinson's patients –A randomized clinical trial

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The effect of self-care education on quality of life of Parkinson's patients –A randomized clinical trial

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Abstract

Introduction: Parkinson disease (PD) is the second most commonly damaging disease of the central nervous system and one of the common causes of inability in the elderly that affects quality of life. **Methods:** This was a randomized clinical trial study over a 6-month period of 69 patients with PD treated in Imam Reza Hospital in Shiraz from April to October 2016. The patients were randomly allocated into experimental (n=34) and control (n=35). Experimental group received self-care training. The de Boer (1996) quality of life questionnaire in both groups were completed before intervention and after 1, 2-months. The quality of life questionnaire has five subscales included Parkinson's symptoms, systemic symptoms, emotional functioning, and social function. Cronbach's alpha in all questionnaire subscales was 0.95, SPSS (version 19) software was used to data analyses and using ANCOVA. **Result:** 69 patients with Parkinson disease included 36(52.17%) male and 33(47.83%) female enrolled in study. Marital status and employment status in the control and experimental group have a significant difference (respectively P=0.003 and P=0.01). It was observed self-education improved scores of quality of life subscales included Parkinson's symptoms score of in the post-test (P = 0.001), systemic symptoms in the post-test (P = 0.05). emotional function in the post-test (P = 0.05). social function score in the post-test (P = 0.05) in intervention group. There were not statistical difference of scores of quality of life in 1 month and 2 months after treatment (P>0.05). **Conclusion:** The findings of this study show the application of self-care program to improve the quality of life of patients with PD and this effect was stable after 1 month of treatment.

Key words: education, quality of life, Self-care, Parkinson disease



Introduction

Parkinson disease (PD) is one of the major degenerative diseases of the central nervous system. PD after Alzheimer's is the second most common neurodegenerative disorder in the elderly, resulting in a significant reduction in the functional and motor abilities of individuals (1-3). Increasing the age and life expectancy increases the risk of PD. It affects approximately 1.8% of people over the age of 65 years (4). Although the mean age is 60 years old, studies show that between 5% and 10% of the population of PD experience the disease before the age of 40(5). Findings from studies on neurological diseases, such as PD, show that in most of these diseases, the function of the basal ganglia is impaired. Basal ganglia are an important neuronal network for motor function that is involved in the planning and execution of movements (6). PD is caused by the progressive degeneration of dopaminergic cells of Substantia Nigra in the basal ganglia (7). Substantia Nigra modifies the movements. When the Substantia Nigra cells die, the level of dopamine in the corpus striatum and other parts of the brain decreases, neural communication is disturbed as a result part of the central nervous system that is controlling the muscles of the body is interrupted. This ultimately leads to certain motor disorders such as status instability, Brady kynesia, tremor, and stiffness. Tremor is generally one of the earliest symptoms of the disease are reported to the doctor first visit (8, 9). In the process of developing this disease, physical and psychological problems is created that reduces individual autonomy, feeling inadequate and, in general, reducing the quality of life of the individual (10). Despite modern studies, there was still no definitive and eradicating treatment for this disease and most existing treatments can reduce symptoms or slow down the progression of the disease (11, 12). Therefore, maintaining and improving the quality of life of patients is one of the most important goals of health-care systems (13). One of the main issues in improving the quality of treatment is the participation of the patient in the treatment and care of themselves (14). The proper training can prevent the progression and disability of the disease (15). Since nurses spend the most time with patients, they are often in the best position to discover the invisible symptoms that the patient experiences. Therefore, they can determine the educational needs of patients and provide a training program tailored to each patient (16). When the patient's level of education is maximized, their ability to decide and act increases and their compatibility mechanisms are increased. Hence, the purpose of patient education is to help the patient to take on more self-care responsibilities and to help them adapt to the changes that have occurred in their physical and practical state of affairs (17, 18). The patient's lack of knowledge about self-care can lead to negative consequences for patients' health and hospitalization (19). Many researchers are trying to study, evaluate, and develop interventions to control the problems of these patients, So that several research activities in this field are ongoing or ongoing. Khalaji et al. reviewed the effect of physical activity on functional readiness and quality of life of people with PD. The findings of this study showed the role of functional activities in improving functional readiness and quality of life in PD and these exercises are positively related to the independence of these people for daily tasks and the enjoyment of a better life (20). In addition, in other studies have been shown that the implementation of the educational program will improve the quality of life of these patients(10, 16, 21).

Medical treatments do not have a significant impact on the quality of life of these patients; therefore appropriate interventions to control the disabling problems of PD and improve their quality of life by the therapeutic team are essential(22, 23). Stimulating the self-care capacity of these patients and planning on this is important to them (16). Therefore, considering the above, we need to study and design the latest and, at the same time, the most effective self-care



program to improve the quality of life of PD. In Iran, there is not much research about the impact of self-care program on the quality of life of patients with PD. Therefore, a study was conducted to determine the effect of self-care education program on quality of life in PD.

Methods

The present study was a randomized clinical trial with intervention of control groups by pretest and posttest design performed. A total 69 Parkinson's patients were included in study who were referred to Imam Reza clinic in Shiraz University of Medical Sciences over the 6-month period from April to October 2016. Based on the previous studies on quality of life and effect of self-care education (18) and the statistical formula for determining sample size (where $\alpha=5\%$, $\beta=0.2$, $S_1=20.6$, $S_2=10.2$, $d=11.21$) in intervention research with confidence interval of 95% and test power of 80%, necessary number of samples in each group was determined as 33 people and was considered 35 people for more confidence. Hence, the total sample size was 69 (34 patients and 35 controls).

$$n = \frac{(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta})^2 (s_1 + s_2)^2}{d^2}$$

Inclusion criteria were the primary diagnosis of Parkinson's is confirmed by a neurologist based on UK Parkinson's Disease Society Brain Bank Diagnostic Criteria. Lack of dementia, Lack of confirmed mental illness and mental retardation or other chronic diseases because of preventing of their self-care activities. Exclusion criteria were somatic diseases with a potential relevant effect on mood, cognition, or quality of life (advanced cerebrovascular diseases or sequelae; chronic pain syndromes; chronic inflammatory/infectious diseases; advanced diabetes mellitus; malignancy; renal, hepatic, or heart failure; severe anemia or any other severely debilitating or life-threatening disease/state), participation in similar educational programs at the same time, reluctance of the patient to continue participation and not spending of all training sessions.

Data collection was applied in this study by using demographic information questionnaire and standard instrument for investigation of quality of life of the patients with Parkinson disease (de Boer 1996). This questionnaire consists of 37 items and measures quality of life in four subscales included Parkinson's symptoms (14 Items), systemic symptoms (7 Items), emotional functioning (9 Items), and social function (7 Items). The score of each item was based on 5 Likert Spectrum from 1 for the "always" option to 5 for the "never" option. The range of scores for the entire questionnaire was from 37 to 185 variables, which was a higher score for higher quality of life. The reliability and validity of this questionnaire has been verified in a sociocultural context of Iran. Construct validity of PD Questionnaire (de Boer 1996) including the range of convergent validity was 0.42-0.83 and that of discriminate validity was 0.15-0.70. Reliability was determined as Cronbach's alpha 0.95 for all subscales and for Parkinson's symptoms (0.87), Systemic symptoms (0.75), Emotional function (0.81), social function (0.87) (24). (Nurbekova et al., 2018)

Sampling method was based on convenient sampling and all patients who had the inclusion criteria were entered the study. The patients were allocated randomly into two groups of experimental and control and study was applied in single-blinded protocols. All the subjects were asked to submit an informed written consent. Immediately upon recruiting the subjects to the study, they were asked to fill out the two-part questionnaire including demographic and



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quality of life information. The subjects filled out the questionnaire. Ethics committee of Shiraz University of Medical Sciences approved the content of the study (IR.SUMS.REC.1395.155).

The intervention group was divided into four small groups and a training program in 6 sessions of 45 minutes in six weeks, held one day a week, for the intervention group. At the end of each session, the pamphlets for the meeting were presented to the samples. During this time, the researcher, either on-face or on the phone monitored the implementation of the program in the intervention group, responded to their questions and mistakes in the implementation of the program, and patients were guided to better implement the program. Control group received routine treatment caring process. After 1 month (Posttest) and 2 months(Follow up) from the implementation of the program, the quality of life questionnaire was again investigated in the intervention and control group and all subjects completed the quality of life of Parkinson patients questionnaire . The content of resent study was confirmed by Ethics Committee of the Shiraz University of Medical Sciences.

The intervention group received self-care education to provide information and awareness on the proper care, including how to balance, tremor prevention, stiffness control and Brady Keynesian, stability in the situation, stress compliance, prevention negative effects of the disease on various aspects of patient's life, reducing problems and improving the quality of life, using relaxation methods, providing mental health.

The data were collected before, one month and two months after the implementation of the program in both groups and analyzed by a descriptive and deductive statistics. (Villalobos Antúnez and Ganga, 2016) To study distributive homogeneity of demographic features in both interventional and control groups, chi-squared and Exact Fisher's tests were applied. To compare of mean quality of life scores in different times ANCOVA were applied and SPSS (version 19) software was used to data analyses in **[Figure 1]**.

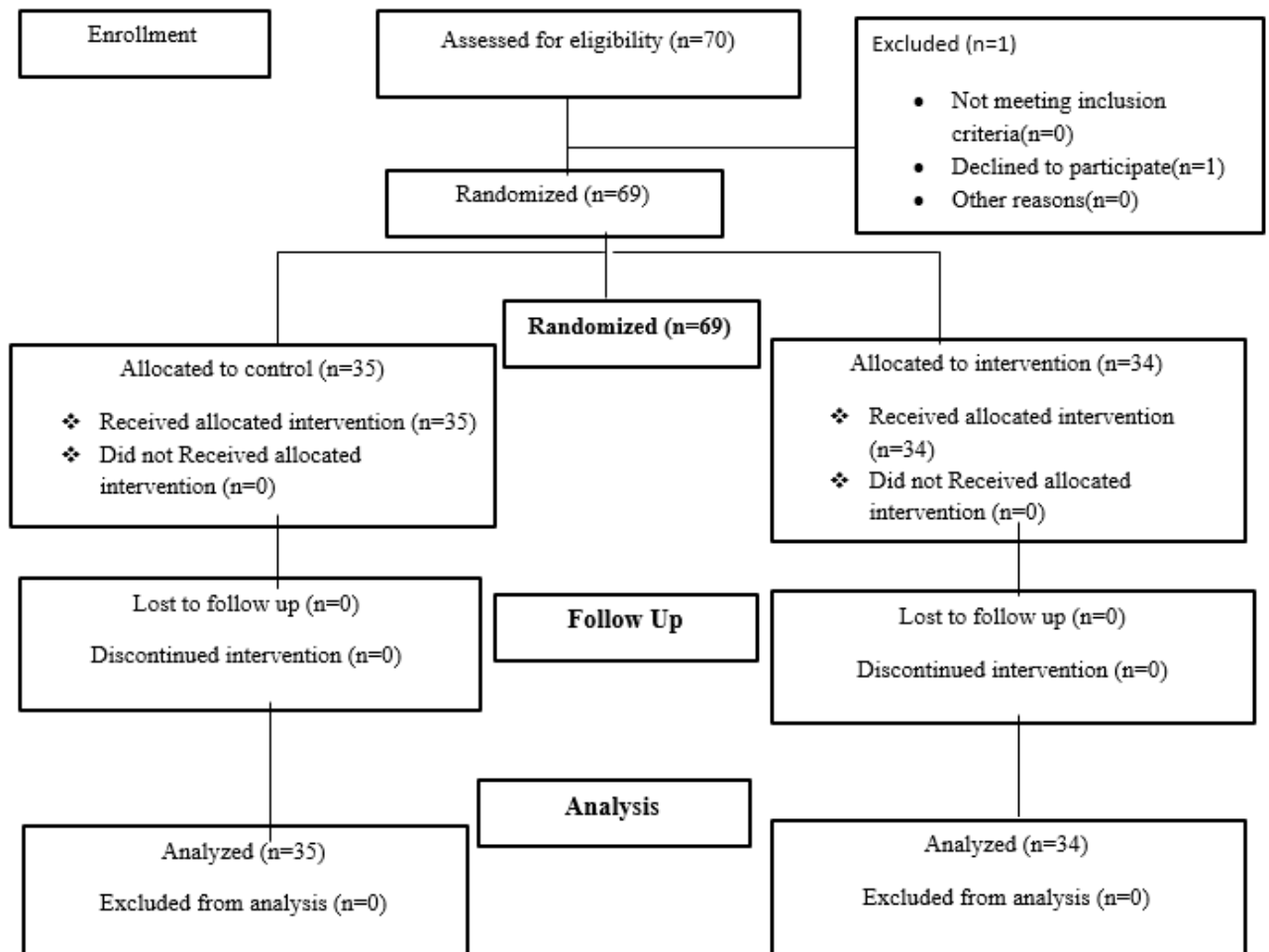


Figure 1. CONSORT flow diagram of the participants

The frequency distribution and the percentage of age group in the control and interventional groups are shown in [Table 1]. The chi-square and fisher exact test showed there is no significant difference in gender, age, education status, and duration of illness in the control and experimental group and the matching for these variables is done correctly. Marital status and employment status among the all patients have a significant difference ($P=0.003$ and $P=0.01$ respectively).

The mean and standard deviation of the quality of life subscales in the control and Interventional groups were stated in table two before and after the intervention. It is observed that the mean score of all subscales of quality of life in intervention group after 1 month and 2 months treatment increased compared with control group [Table 2].

In [Table 3], the results of Multivariate Lambda Wilkes test for investigation of the effect of time, group and interaction effect of time and group were shown. The results of this analysis with regard to F and significance level show that the effect of time, group and interaction effect of time and group on the dimensions of quality of life is significant. As seen from the [Table



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3], the impact of time on the quality of life scores is significant. In other words the difference between the mean scores of quality of life at different times varies according to the variables of the group.

The results of [Table 4] show that there were significant differences between control and intervention groups in the Parkinson's symptoms, systemic symptoms, emotional function, and function. Also, self-care education improve PD patients' quality of life in related of Parkinson's symptoms (P = 0.001 and F = 13. 13), systemic symptoms test (P = 0.006 and F = 9.63), emotional function P = 0.04 and F = 11.81), social function (P = 0.03 and F = 4.84). And effect size is 0.32, 0.19, 0.22, and 0.15 respectively.

Therefore, the significance hypothesis of the difference between the two groups in the post-test was confirmed after the probable elimination of the pre-test. The effect size of each subscales was 0.32,0.19,0.23 and 0.15 for Parkinson's symptoms , systemic symptoms, emotional function and social function respectively which means 32.7%, 19.7%,23.3%,15.2% of self-care education improved Parkinson's patients quality of life [Figure 2].

Table 1. The frequency distribution and the percentage of demographic status in the control and interventional groups.

Variable	Control group N(%)	Intervention group N(%)	p*
Sex	17 (48.6)	19 (55.9)	0.44
Male	18 (51.4)	15 (44.1)	
Female			
Age	2 (5.7)	2 (5.9)	0.55
40-50	9 (25.7)	9 (26.5)	
50-60	17 (48.6)	14 (41.2)	
60-70	7 (20)	9 (26.5)	
Up to 70			
marital status	3 (8.6)	8 (23.5)	0.003
single	32 (91.4)	26 (76.5)	
married			
employment status	10 (28.6)	2 (5.9)	0.01
Employed	13 (37.1)	6 (17.6)	
Retired	12 (34.3)	26 (76.5)	
Unemployed			



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Education	under the Diploma	24 (68.6)	17 (50)	0.31
	Diploma Higher	3 (8.6)	10 (29.4)	
Duration of PD ^a	less than 1 year	8 (22.9)	7 (20.6)	0.56
	1to 5 years	10 (28.6)	10 (29.4)	
	5to 10 years	16 (45.7)	14 (41.2)	
	More than 10 years	5 (14.3)	9 (26.5)	
		4 (11.4)	1 (2.9)	

* significant level of χ^2

a= Parkinson disease

Table 2: Mean \pm standard deviation of quality of life and subscales s before and after two months of self – education in control and interventional group.

Variable	group	Mean \pm SD Pre-test	Mean \pm SD Post-test	Mean \pm SD Follow up	p with in
Parkinson's symptoms	control	39.87 \pm 6.65	39.80 \pm 5.96	39.73 \pm 6.24	0.91
	intervention	38.96 \pm 4.32	42.18 \pm 5.96	43.10 \pm 5.35	0.001
	p between	0.12	0.02	0.01	
Systemic symptoms	control	21.35 \pm 2.52	22.08 \pm 2.35	21.39 \pm 2.12	0.73
	intervention	25.81 \pm 2.98	24.68 \pm 2.65	21.81 \pm 2.15	0.006
	p between	0.21	0.29	0.81	
Emotional function	control	27.33 \pm 3.63	27.88 \pm 3.95	27.78 \pm 3.94	0.65
	intervention	26.79 \pm 3.39	29.59 \pm 3.87	32.18 \pm 4.04	0.04
	p between	0.09	0.04	0.02	
Social function	control	21.36 \pm 3.57	22.19 \pm 2.54	21.89 \pm 2.81	0.35
	intervention	27.28 \pm 2.52	25.35 \pm 4.96	27.12 \pm 4.36	0.03
	p between	0.002	0.03	0.001	
	control	109.91 \pm 8.63	111.95 \pm 7.49	110.79 \pm 6.85	0.81



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Total Quality of Life	intervention	108.84±7.09	121.81±9.08	128.21±9.12	0.001
	p between	0.07	0.001	0.001	

Table 3. The results of Multivariate Lambda Wilkes test for investigation of the effect of time, group and interaction effect of time and group

Effect		Test	Value	F	p	Eta
Between groups	Group	Wilks lambda	0.13	22.10	0.001	0.91
Within groups	Time	Wilks lambda	0.06	24.30	0.001	0.96
Interaction	Time*Group	Wilks lambda	0.06	28.50	0.001	0.97

Table 4. Results of ANCOVA test on the mean post-test scores of two groups with pre-test control

Variable	Group	Sum of squares	df	Mean Square	F	p	Effect size
Parkinson's symptoms	Pre-test	0.28	1	0.28	0.49	0.48	0.01
	Group	7.57	1	7.58	13.13	0.001	0.32
Systemic symptoms	Pre-test	7.33	1	7.33	0.35	0.31	0.21
	Group	6.71	1	6.71	9.63	0.006	0.19
Emotional function	Pre-test	1.87	1	1.87	0.45	0.22	0.06
	Group	0.63	1	0.63	11.81	0.04	0.22
Social function	Pre-test	0.90	1	0.90	0.46	0.38	0.02
	Group	5.70	1	5.70	4.84	0.03	0.15

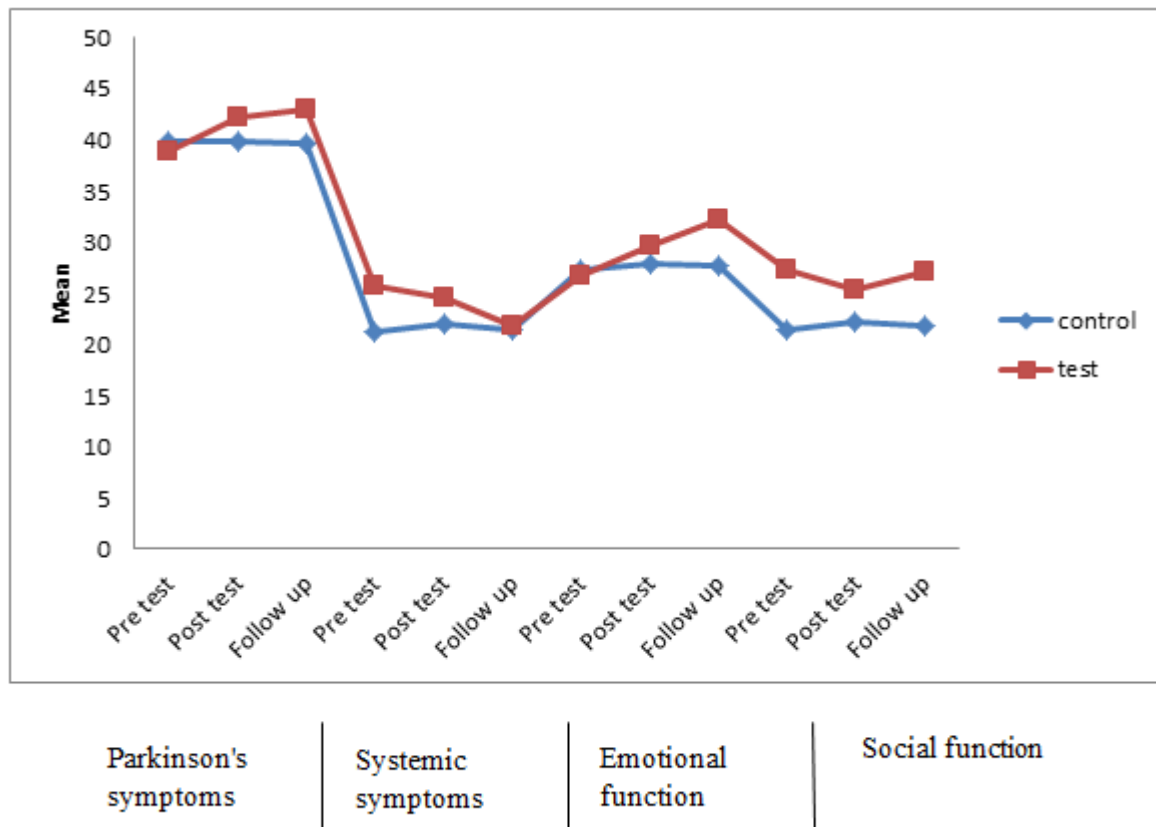


Figure 2. Mean score of quality of life dimensions in Intervention and control group through pretest, posttest and follow up.

Discussion

Regarding the effect of self-care program on the quality of life of patients with PD in the present study, the effect of this program on the four subscales of quality of life in the intervention group was in the positive direction. The impact of this program on Parkinson symptoms and emotional function subscales have been quite tangible. In other subscales, quality of life included systemic symptoms and social functioning in a positive direction. The fact that self-care by the patient with Parkinson can lead to increased abilities in the patient, Self-care programs can enhance motivation and self-esteem in these patients so that they will improve their ability to take care of themselves and improve their disabilities and help self-care to solve these problems. In the control group, the mean score of Parkinson's symptoms fell by one month and two months after the intervention, the nature of PD seems to have affected this subscales.

In this study, it was shown that the quality of life of patients before intervention was low in both groups. The results of this study are consistent with the results of some studies. As Sarah et al. concluded in their study that PD quality of life was significantly reduced compared with normal people (25). Similarly, Dan Oudstone et al. (2007) concluded with the study of quality of life and its associated concepts in Parkinson's patients that PD quality of life is low compared to other people and chronic illnesses (26). On the other hand, Rodríguez-Violante et al(2015) showed that quality of life in 250 Parkinson's patients and caregivers has decreased (27). In other study by Farid Chanci et al Concluded the quality of life of Parkinson's and dementia is



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low, especially in the field of physical function (28). A study by Pandey et al., in 2016, found that Parkinson's patients with sleep disorders had a poor quality of life (29). In a study conducted by Chang et al in 2016, Parkinson's patients with depression, disability, and cognitive impairment have low quality of life (30). A study by Onozawa et al. In Japan in 2016 showed that the early morning akinesia is commonly found in Parkinson's patients, even in the early stages of the disease, which reduces the quality of life in these patients and their caregivers (31). Burganzo et al. in their study, 103 Parkinson's patients showed that quality of life in Parkinson's patients with motor and non-motor symptoms is reduced (32). Also, in a study by Lawson et al in 2016 on 212 Parkinson's patients with cognitive impairment in the UK, it was concluded that Parkinson's patients with moderate cognitive impairment have low quality of life, and Parkinson's patients with dementia have a high quality of life Lower (33). But in a 2014 study by Hechtner et al., In which 817 PD patients were collected cross-sectionally in France, Germany, Italy, Spain, and the UK at the early stages of PD were evaluated to assess the motor side effects on quality of life in patients, the quality of life in patients who were in the first 2 years of their illness and under treatment is not significantly reduced (34). Perhaps this discrepancy with the present study is due to the fact that these patients are at an early stage of the disease and the symptoms of the disease are well controlled with treatment and have not had a significant impact on their quality of life.

The results of this study about highest and lowest mean scores of quality of life subscales are in line with a study done by Reuther et al. (2007), which evaluated the quality of life in 145 Parkinson's patients using the PDQL questionnaire. They reported the highest mean of quality of life associated with Parkinson's symptoms and the lowest mean of quality of life associated with the subscales Systemic Symptoms (35). In present study we showed that self-care education can improve Parkinson's symptoms and emotional function of patients obviously. In other studies noted that emotional and psychological function of Parkinson patients can positively predict quality of life in Parkinson patients (36, 37). The better psychological property was associated with patients more conscientious. Patients with high conscientious are able to solve many problems and apply much mechanisms with strong attention regulation, which allows them to disengage from negative thoughts allowing them to have a better psychological health (38-40). Therefore the effect of self-care education on emotional function of Parkinson patients may be reflect the potential effect of self-care education on personality traits to recovery of patients and improvement of life quality (41, 42).

In the present study, the mean scores of quality of life and its subscales in the experimental group were increased one month after the intervention. The results showed that self-care education had an impact on improving the quality of life of patients with PD. As Chlond et al. In their 2015 study on 34 Parkinson's patients showed an 8-week training program, for PD after 3 months increased the quality of life and adapted to the disease (3). Also, in a study by Campo et al in the Netherlands in 2009, the benefits of this training program were on Parkinson's patients and caregivers. The study showed that the educational program reduces the psychosocial problems of patients and their caregivers and also reduces their need for help. Patients in the intervention group had higher quality of life than the control group. The result is that educational programs improve the quality of life of Parkinson's patients and caregivers (16).

The physical and cognitive problems of PD have an impact on their quality of life and make it difficult for them to do their daily activities. The self-care program is a non-pharmacological, non-invasive and low-cost method for controlling physical and psychological problems and is



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easily taught to the patient and his or her family through medical personnel, including nurses. So that one of the responsibilities of the nurses is to manage these problems, which are the most influential factors in quality of life, to transfer information about self-care and follow up and support the implementation of these programs.

In present study we found self-care educational protocol was practical easy to doing for patients with Parkinson. In addition the other strength point of our study was to follow-up of patients after one month of intervention that show the result of our study had stability over the time in other words effects of self-care educational protocol could preserved in long time. However some limitations such as the lack of patient literacy and their lack of familiarity with new communication technologies such as mobile phone, and difficult access to them inhibit to obtain best result.

Conclusion:

We concluded the use of self-care education protocol can be improve all aspects of quality of Parkinson patients. Paying attention to self-care education programs as an educational protocol to patients and families by medical personnel, especially nurses have been importance effect in controlling of complications after disease that influenced on life quality. We suggest in future study, self-care education apply on other disease with more sample size and other social and psychological factors affecting the their quality of life be will be investigate. Due to the expansion of communications and the advancement of technology, the implementation of the self-care process through telephone and internet pages can also be considered in the future.

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Conflict of interest

There were no conflicts of interest among the authors of the study.

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