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# RESEARCH

# ASSESSMENT OF THE IMPACT OF DEMENTIA CARE AND SUPPORT PROGRAM IN BOTH PATIENT AND CAREGIVER OUTCOMES: AN INTERVENTION STUDY

# Abstract

*Introduction:* Dementia is one of the priority issues among the public health concerns. This study aims to assess the impact of the Dementia Care and Support Program in caregivers and patients with dementia.

**Materials and Methods:** This study is an intervention study. Dementia Care and Support Program was a planned 16-week program. Sixty-one patient–caregiver pairs were randomized into two groups, the intervention (n=31) and control groups (n=30). Dementia Care and Support Program was applied to the intervention group, but the control group received routine hospital care. Data were collected between July and November 2016 from a dementia outpatient clinic. While data for patients were collected using the quality-of-life assessment in Alzheimer's disease and Neuropsychiatric Inventory, data for caregivers were collected using the quality of life SF-36, Beck Depression, Beck Anxiety, and Zarit Caregiver Burden Care Inventory.

**Results:** Fifty-four patient–caregiver pairs completed the study. The mean age of the patients was 76.7 $\pm$ 11.2 (46–96) years old. There was no statistically significant difference in the quality-of-life scores and neuropsychiatric symptom scores between the patient groups (p>0.05). The mean age of caregivers was 53.6 $\pm$ 14.8 (22–81) years old. Statistically significant differences were found in NPI-D, quality-of-life mental health, quality-of-life physical health, depression, and anxiety scores between the caregiver groups (p<0.05), but there was no statistically significant difference in burden scores (p>0.05).

**Conclusion:** This study established that Dementia Care and Support Program has positive effects on caregivers.

Keywords: Dementia; Patient; Caregiver; Quality of Life; Depression.

# ARAŞTIRMA

# DEMANS BAKIM VE DESTEK PROGRAMININ HASTA VE BAKIM VERİCİ ÇIKTILARI ÜZERİNDEKİ ETKİSİNİN DEĞERLENDİRİLMESİ: BİR MÜDAHALE ÇALIŞMASI Ö7

*Giriş:* Demans halk sağlığı sorunları arasında öncelikli bir konudur. Bu çalışmanın amacı demanslı hastaların bakım vericilerine uygulanan Demans Bakım ve Destek Programı'nın etkisini değerlendirmekti.

*Gereç ve Yöntem:* Bu çalışma 16 haftalık bir müdahale çalışmasıdır. Çalışmada 61 hastabakım verici çifti iki gruba randomize edildi. Girişim grubu 31, kontrol grubu 30 kişiden oluştu. Girişim grubuna Demans Bakım ve Destek Programı uygulanırken, kontrol grubuna rutin hastane bakımı verildi. Veriler Demans polikliniğinde 2016 Temmuz-2016 Kasım tarihleri arsında toplandı. Veri toplamada hastalar için Alzheimer Hastalığı Yaşam Kalitesi Ölçeği ve Nöropsikiyatrik Envanter kullanılırken; bakım vericiler için Yaşam Kalitesi SF 36 Ölçeği, Beck Depresyon Ölçeği, Beck Anksiyete Ölçeği, Zarit Bakım Yükü Ölçeği kullanıldı.

**Bulgular:** Çalışma 54 bakım verici-hasta çifti ile sonlandırıldı. Hastaların yaş ortalaması 76.7±11.2 (46-96) idi. Hastaların yaşam kalitesi puanlarında ve nöropsikiyatrik semptom ciddiyeti (NPI-S) puanlarında gruplar arasında istatistiksel olarak anlamlı bir fark bulunmadı (p>0.05). Bakım vericilerin yaş ortalaması ise 53.6±14.8 (22-81) idi. Bakım vericilerin distress (NPI-D) puanlarında, yaşam kalitesi puanlarında, depresyon ve anksiyete puanlarında gruplar arasında istatistiksel olarak anlamlı fark bulundu (p<0.05). Fakat, bakım verici yükünde gruplar arasında istatistiksel olarak anlamlı bir fark bulunmadı (p> 0.05).

**Sonuç:** Bu çalışma, Demans Bakım ve Destek Programı'nın demans hastalarının bakım vericileri üzerinde olumlu etkisi olduğunu ortaya koymaktadır.

Anahtar Sözcükler: Demans; Hasta; Bakım Verici; Yaşam Kalitesi; Depresyon.



# INTRODUCTION

Dementia is a rapidly growing global public health problem. Approximately 50 million people have dementia worldwide, and most of them live in lowand middle-income countries. Nearly 10 million new cases are discovered annually (1). Dementia rises exponentially during old age; it is one of the leading causes of disability and dependency among the elderly (2). Dementia is often seriously devastating for both patient and caregiver or family. Family caregivers who are informal caregivers experience burden, depression, anxiety, healthrelated problems, and financial difficulties (1,2).

Dementia care aims to preserve patients' functioning, decrease disability, regulate the environment and relationships to sustain stability, and maintain personality and quality of life (3). Nurses are accountable for providing education, information, and support to caregivers during all stages, which is the first and fundamental step among the non-pharmacological approaches (3, 4). Based on evidences, public health nursing practices in dementia care aim to maintain quality results despite differences in patient care outcomes, standardized care, and enhanced nurse satisfaction (5).

The program used in this research was Dementia Care and Support Program (DCSP), which was developed by the authors from the literature review (6, 7). This was a multicomponent psychosocial intervention. The psychosocial intervention for family and/or informal caregiver attempts to increase knowledge (education), improve skills and coping strategies, and provide support (7). In the recent years, several authors have assessed the efficacy of interventions for both caregivers and dementia patient, but they have found considerable variability in the outcome. The DCSP consists of both individual (telephone interviews and home visits) and group support intervention (group training, face-to-face group meeting, WhatsApp group interviews). When the literature was examined, only two nursing researches (8, 9) were found in Turkey. This situation has increased the interest in conducting research about the subject. This study aims to provide evidence for the impact of multicomponent and multidisciplinary interventions on both patient and caregiver outcomes.

# MATERIALS AND METHOD

### Study design

This study is intervention study.

### Participants

This study was conducted at Manisa Celal Bayar University (MCBU) Hafsa Sultan Hospital Dementia Outpatient Clinic in Manisa, between July and November 2016. The study universe comprised clinic-registered patients (N = 396) and their caregivers (family caregivers). We computed the sample size with power analysis, statistically based on the work of Martin-Corasso et al. (10). The power analysis for this study, at 99% power and 0.01 error level, was therefore determined that 38 patient-caregiver pairs (19 patient-caregiver pairs in each group) were required. Considering loss of subjects over time, we initiated the study with 61 patient-caregiver pairs. The study sample was selected by probabilistic sampling among patient-caregiver pairs that fulfilled the inclusion criteria.

The inclusion criteria for patients were as follows: clinical diagnosis of dementia; living in Manisa; not leaving Manisa during the study period and willing to participate in the research. The exclusion criterion was diagnosis with cancer. We enrolled caregivers based on the following criteria: aged 18 years; living in Manisa; not leaving Manisa during the study period and willing to participate in the research.

Randomisation criteria were dementia type, dementia stage and caregivers' education level. We stratified the patients and caregivers based on the education status of caregivers, considering the randomisation criteria. Using simple random placement method, we determined groups of caregivers to be assigned to the groups. The patient-caregiver pairs were assigned to the randomised IG (n = 30) and CG (n = 31). We evaluated the homogeneity of randomisation using the  $x^2$  test. Figure 1 shows the study flowchart.

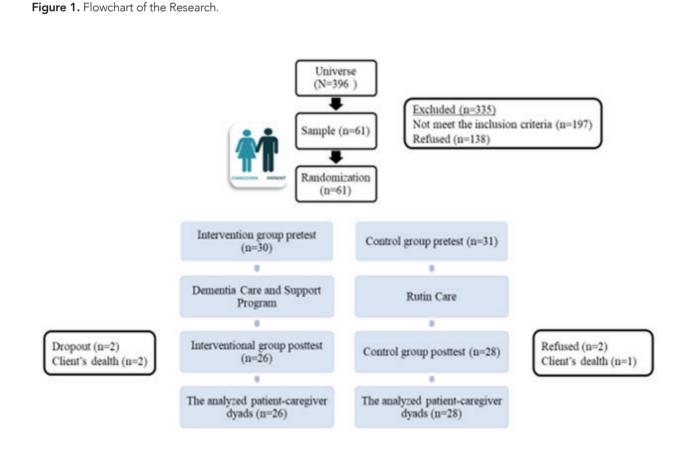
#### Procedures

The programme with multi-component interventions was given by a multi-disciplinary team (nurse, neurologist, psychologist). Dementia type and its stages were diagnosed by a neurologist.

#### Intervention group

The group received group training and support, home visits and individual support through telephonic interviews. Caregivers were unable to attend group training when they could not find anyone to leave their patients. This handicap was tried to be overcome with the WhatsApp group and house visits. WhatsApp group was set up to make caregivers communicate and interact with each other and researchers. During 16 weeks, caregivers were interviewed routinely per month; four face-to-face interviews were conducted with each patient–caregiver dyad.

After pre-test, intervention group was trained with a structured standard training package



(Fig. 2); the training comprised videos, oral presentation, question-answer sessions. Training programme created by the researchers and the study plan were explained to the caregivers in writing. In some training sessions, psychologist at the dementia clinic played a supporting role (stress management and problem-solving methods). Furthermore, caregivers provided support for individual problems.

# Control group

We interviewed the CG (n = 31) two times during the data collection process. The group received just routine hospital care. At the end of 16 weeks, the programme was provided to this group too.

### Data collection

Caregiver and Patient Information Form: The form prepared by referring to the literature (10, 11). was comprised of two sections. Firstly section was about patients' age, sex, education level, marital status, dementia type and stage, comorbidity etc. Secondly section was about caregivers' age, sex, education level, marital status, income status, relationship with patients etc.

Patients Quality-of-life in Alzheimer's Disease (QoL-AD): The scale developed by Longsdon et al. (1999) was filled and assessed separately for patients and caregivers. The scale measures quality of life of Alzheimer's patients. The scale comprises 13 items of the Likert type, and quality of life increases as the score increases. Akpinar &Küçükgüçlü (2012) assessed the Turkish reliability and validity of the and Cronbach's  $\alpha$  to be 0.84 (12). In this study, Cronbach's  $\alpha$  was 0.84.

Neuropsychiatric Inventory (NPI): This assesses the frequency and severity of psychological and behavioural symptoms of dementia and is based on interviews with caregivers. It comprises two parts as follows: (a) measures the severity of associated problem behaviours on a scale of 1–3 (NPI-S) and (b) measures the perceived distress of problem behaviours by caregivers on a scale of 0–5 (NPI-D). Akça-Kalem et al. (2005) evaluated Cronbach's  $\alpha$  of the inventory to be 0.79. For specific items of the frequency and severity, Cronbach's  $\alpha$  varies between 0.76 and 0.79, respectively (13). In this study, Cronbach's  $\alpha$  of the inventory was 0.91, and for specific items of the frequency and severity Cronbach's  $\alpha$  values were 0.73 and 0.77.

# Caregivers

Quality of Life Scale SF36 comprises eight subdimensions and defines two summary areas: mental health and physical health. The total score can be 0-100. Koçyiğit et al. (1999) assessed the Turkish reliability and validity of the scale. Cronbach's  $\alpha$  of the scale was 0.73-0.76 for sub-dimensions of the scale (14); in this study, it was 0.73-0.88.

The Beck Depression Inventory (BDI) was developed by Beck et al. (1961) and enables the assessment of both depressive symptoms and cognitive content. The total score can be 0–63 points. Hisli (1989) assessed the Turkish validity and reliability. The total score can be 0–63 points. Cronbach's  $\alpha$  was 0.80 (15); in this study, it was 0.80.

Beck Anxiety Inventory (BAI) is a 21-item Likerttype scale, developed by Beck et al. (1988), to determine the frequency of anxiety symptoms of individuals. The severity of anxiety increases as the total score of the scale increases. The total score can be 0–63 points. Ulusoy (1998) established the Turkish validity and reliability of the scale. Cronbach's  $\alpha$  of the scale was 0.93 (16); in this study, it was 0.87.

Zarit Burden Interview (ZBI) the most widely used in caregiver burden. It encompasses the physical, emotional and financial burden as perceived by the caregiver. It asks 22 questions that are rated on a five-point scale (0 = not at all to 4 = nearly always). Cronbach's  $\alpha$  for the validity luck study of the scale was 0.95 (17); in this study, it was 0.91.

# Statistical analysis

Statistical analyses were performed using



the SPSS 15.0 software package. We evaluated descriptive characteristics using numbers and percentages and binary comparisons using the  $x^2$  test. We considered the statistical significance at 0.05. Data of the normal distribution are presented by the number of sample size and Shapiro–Wilk values. Furthermore, non-parametric tests were used to analyse non-normally distributed variables.

#### Ethics

The study was approved by the MCBU Medicine Faculty Local Ethics Board (dated 9 December 2015; No: 20478486-412), MCBU Hafsa Sultan Hospital. We obtained written informed consent from all caregivers and some of the patients through the Volunteer Form.

### RESULTS

We assessed the research findings in two parts – patients' and caregivers' results.

### Patients' results

The mean age of the patients was 76.7  $\pm$  11.2 (46–96) years old. We observed no statistically significant differences between the groups for all demographic characteristics (p > 0.05), except for marital status (p < 0.05; Table 1).

**Table 1.** Socio-demographic and descriptive characteristics of patients (n = 61)

Variable		Intervention Group (n = 30)	Control Group (n = 31)	X <sup>2</sup> test*
	1	n (%)	n (%)	X²,p
A	≤76 years	9 (40.9)	13 (59.1)	$x^2 = 0.942$
Age	>76 years	21 (53.8)	18 (46.2)	p = 0.332
C	Female	23 (52.3)	21 (47.7)	$x^2 = 0.604$
Sex	Male	7 (41.2)	10 (58.8)	p = 0.437
	Illiterate	8 (66.7)	4 (33.3)	
	Literate	3 (25.0)	9 (75.0)	
Education	Primary School	15 (62.5)	9 (37.5)	$x^2 = 8.019$
Level	Middle School	1 (25.0)	3 (75.0)	p = 0.155
	High School	2 (40.0)	3 (60.0)	
	University	1 (25.0)	3 (75.0)	
Marital Status	Married	10 (30.3)	23 (69.7)	$x^2 = 10.250$
	Single	20 (71.4)	8 (28.6)	p = 0.001



Variable		Intervention Group (n = 30)	Control Group (n = 31)	X² test*	
		n (%)	n (%)	Х²,р	
	Alzheimer's Disease	23 (46.0)	27 (54.0)		
	Туреа	1 (50.0)	1 (50.0)	x <sup>2</sup> = 2.104 p = 0.717	
Dementi Typeª	Dementia with Lewy Bodies	1 (50.0)	1 (50.0)		
	Mixed Dementia	1 (50.0)	1 (50.0)		
	Parkinson's Disease Dementia	4 (80.0)	1 (80.0)		
Dementia Stageª	Very Mild (0.5)	2 (50.0)	2 (50.0)		
	Dementia Stagea	11 (47.8)	12 (52.2)	$x^2 = 3.710$	
	Moderate (2)	12 (66.7)	6 (33.3)	p = 0.295	
	Severe (3)	5 (33.3)	10 (66.7)		
Comorbidity	Yes	21 (47.7)	23 (52.3)	$x^2 = 0.133$	
	Comorbidity	9 (52.9)	8 (47.1)	P = 0.715	

Abbereviations:  $x^2$  test; a Randomisation criteria.

There was no statistically significant difference in quality-of-life scores and neuropsychiatric symptom scores between the groups (p > 0.05; Table 2).

#### Caregivers' results

The mean age of caregivers was  $53.6 \pm 14.8$  (22–81) years old. No significant differences were observed between the groups for all demographic characteristics (p > 0.05; Table 3).

The results of the present study demonstrate that there was statistically significant differences in NPI-D, quality-of-life (both mental and physical health), depression, and anxiety scores between the groups (p < 0.05), but there was no statistically

significant difference in burden scores (p > 0.05; Table 4).

### DISCUSSION

Caregivers have critical roles, needs, and difficulties; however, inadequate information about the care provided by the caregivers increases problems for patients as well as caregivers. With the use of structured sessions and information and psychological support investigation, one of the hopes of the 16-week intervention program was to determine whether intervention could affect the outcomes for both caregivers and dementia patients.

			Intervention Group		Control Group	<b>D</b>	
		n	$x \pm SD$ (Min; Max)	n	$x \pm SD$ (Min; Max)	Between groups**	
	Pre-test	22	31.18 ± 6.14 (22; 42)	20	33.29 ± 4.96 (22; 44)	z = -2.054; p = 0.400	
QoL-ADa	Post-test	17	31.79 ± 5.41 (22;39)	17	32.39 ± 4.33 (22; 39)	z = -0.328; p = 0.743	
	Pre-test	30	31.18 ± 23.79 (0; 87)	31	19.41 ± 16.09 (0; 52)	z = -0.845; p = 0.398	
NPI-S	Post-test	26	26.50 ± 21.99 (0; 77)	28	30.70 ± 23.78 (8; 88)	z = -1.013; p = 0.311	

Table 2. Dependent variable scores at pre-test-post-test measures of patients with dementia (n = 61).

Abbereviations: \*Mann–Whitney U-test.; \*\*Wilcoxon marked rank test.; a Calculated solely for Alzheimer's disease; QoL-AD, Quality of life in Alzheimer's Disease; NPI-S, Neuropsychiatric Inventory –Severity.

Variable		Intervention Group (n = 30)	Control Group (n = 31)	X <sup>2</sup> test*
		n (%)	n (%)	Х²,р
	🛙 53 years	18 (58.1)	13 (41.9)	<i>x</i> <sup>2</sup> = 1.991;
Age	>53 years	12 (40.0)	18 (60.0)	p = 0.158
	Female	25 (52.1)	23 (47.9)	$x^2 = 0.759;$
Gender	Male	5 (38.5)	8 (61.5)	p = 0.384
	Illiterate	-(-)	1 (100.0)	
	Literate	2 (50.0)	2 (50.0)	
Education	Primary School	10 (50.0)	10 (50.0)	$x^2 = 0.984;$
Level	Middle School	3 (50.0)	3 (50.0)	p = 0.964
	High School	9 (50.0)	9 (50.0)	
	University	6 (50.0)	6 (50.0)	
	Married	23 (50.0)	23 (50.0)	$x^2 = 0.050;$
Marital Status	Single	7 (46.7)	8 (53.3)	p = 0.823
Income Status	Low Income	4 (30.8)	9 (69.2)	
	Middle Income	24 (55.8)	19 (44.2)	x <sup>2</sup> = 2.689; p = 0.261
	High Income	2 (40.0)	3 (60.0)	

 Table 3. Socio-demographic and descriptive characteristics of caregivers (n = 61).



Variable		Intervention Group (n = 30)	Control Group (n = 31)	X <sup>2</sup> test*
		n (%)	n (%)	<i>Х</i> ²,р
Relationship with Patients	Spouse	4 (25.0)	12 (75.0)	
	Child	19 (63.3)	11 (36.7)	
	Daughter-in-law	6 (54.5)	5 (45.5)	x <sup>2</sup> = 10.211; p = 0.069
	Sibling	1 (100.0)	-(-)	
	Parents	-(-)	1 (100.0)	
	Other	-(-)	2 (100.0)	

Abbereviations:  $x^2$  test; a Randomisation criteria.

		Intervention Group		Control Group		
		n	$x \pm SD$ (Min; Max)	n	$x \pm SD$ (Min; Max)	Between groups**
SF 36	Pre-test	30	41.75 ± 10.00 (26; 52)	31	41.59 ± 9.78 (25; 61)	z = 0.447; p = 0.655
(physical health)	Post-test	26	45.41 ± 7.94 (30; 57)	28	37.74 ± 10.77 (22; 55)	z = 2.372; p = 0.018
SF36	Pre-test	30	41.79 ± 9.024 (17; 55)	31	42.18 ± 10.52 (24; 57)	z = 0.0.736; p = 0.462
(mental health)	Post-test	26	44.87 ± 8.94 (21; 60)	28	39.47 ± 9.39 (27; 57)	z = 2.701; p = 0.007
	Pre-test	30	11.62 ± 8.34 (1; 35)	31	15.23 ± 7.70 (3; 26)	z = 1.525; p = 0.127
BDI	Post-test	26	9.68 ± 8.45 (0; 35)	28	20.64 ± 8.94 (5; 39)	z = 3.268; p = 0.001
DAL	Pre-test	30	10.06 ± 8.89 (0; 30)	31	12.23 ± 8.05 (1; 30)	z = 0.043; p = 0.965
BAI	Post-test	26	6.18 ± 7.26 (0; 29)	28	15.47 ± 9.28 (1; 34)	z = 2.636; p = 0.008
	Pre-test	30	11.87 ± 9.73 (0; 32)	31	9.35 ± 8.06 (0; 27)	z = -0.296; p = 0.767
NPI-D	Post-test	26	10.50 ± 8.70 (0; 27)	28	14.64 ± 10.06 (3; 38)	z = -1.968; p = 0.049
ZBI	Pre-test	30	31.43 ± 18.18 (5; 74)	31	40.17 ± 18.10 (13; 65)	z = 0.599; p = 0.549
		26	27.87 ± 18.39 (5; 63)	28	40.70 ± 17.66 (10; 70)	z = 1.351; p = 0.177

**Table 4.** Dependent variable scores at pre-test-post-test measures of caregivers (n = 61).

Abbreviations: \*Mann–Whitney U-test; \*\*Wilcoxon marked rank test, SF 36, Quality of Life Scale SF36; BDI, Beck Depression Inventory; BAI, Beck Anxiety Inventory; NPI-D, Neuropsychiatric Inventory-Distress, ZBI; Zarit Burden Interview.

Figure 2. The Dementia Care and Support Programme's structured standard training package.

Session	Duration	Theme
Session 1	30 min.	Obtaining information about the patient and the relatives responsible for the care
Session 2	40 min.	What isdementia?
Session 3	30 min.	Dementia treatment (pharmacologic and on-pharmacological treatments)
Session 4	40 min.	Dementia patient care (nutrition, communication, incontinence, sleep, pressure scar
Session 5	30 min.	Importance of family support in the treatment and care of the patient
Session 6	30 min.	Problem solving methods
Session 7	30 min.	Share experience of stress with patients
Session 8	30 min.	Importance of communication in the recovery of patients

#### Patients

The quality of life is an essential parameter in terms of the progression of dementia. Thus, quality-of-life assessment is imperative in planning the care given to the patients. In this study, there was no statistically significant difference in the quality of life between the groups. In the literature, studies on the quality of life of dementia patients are limited. Soylemez et al. conducted an intervention study with a 6-month period while Koivisto et al. made a 3-year follow-up (8, 18). In both studies, no statistically significant difference between the groups in the quality of life (8, 18) was observed. Our findings on the quality of life may be due to the patients' lack of insight and cognitive deficits.

In our study, the intervention provided no beneficial effects on patients' NPI-S score. An 18-month follow-up study provided beneficial results on NPI (11). Our findings are consistent studies both with short intervention period (8, 19) and with long intervention period (18). The findings of some studies and our study (8, 18) supported the idea that neuropsychiatric problems are associated with lower quality of life in patients.

### Caregivers

We observed a marked difference between

the groups in the post-test on both areas of the caregivers' quality-of-life scores. These findings are consistent with some studies when the psychosocial intervention was applied (10, 11). This finding reinforces that modifying the intervention according to the caregiver's needs may result to a successful outcome.

Reportedly, caregivers of patients with dementia are hidden victims who experience mental and physical health-related problems that hinder their ability to cope with stress effectively (20). In this study, the DCSP has a positive effect on depression in the intervention group. This finding is consistent with the study of Kuo et al. (21) while not consistent with the study of Söylemez et al. (8). Our positive findings may have been due to the efficacy of the multicomponent intervention (group training and support, home visits, and individual support through telephone interviews).

This study shows that psychosocial interventions may also decrease the anxiety of caregivers. Akkerman and Ostwald reported that caregivers exhibited a considerable reduction in anxiety scores (22). Santos et al. emphasized the impact of participating in psychosocial interviews, support groups, and education in decreasing the adverse impact of caregiving (23). This result may have been due to the efficacy of having ASSESSMENT OF THE IMPACT OF DEMENTIA CARE AND SUPPORT PROGRAM IN BOTH PATIENT AND CAREGIVER OUTCOMES: AN INTERVENTION STUDY



an individual consultant and support through telephone interviews. Outside of the initiative program, caregivers were able to reach out to the researcher when they needed it.

In this study, significant difference was observed between the groups' NPI-D post-test scores. Reportedly, neuropsychiatric problems are associated with depression symptoms and caregivers' burden (23). Consistent with Dias's findings, the psychosocial intervention positively affected the caregiver distress (19). Our results suggest that providing education and counseling to caregivers decrease their distress.

Upon evaluating the caregivers' burden scores, we did not observe a marked difference between the groups. These findings were consistent with the findings of some previous studies (23, 24). Martin-Corasso et al. continued intervention for 10 months and showed better burden results (10). Caregiver burden encompasses the physical and psychological well-being, social life, and financial status. In this study, it was thought that this resulted to caregivers' physical and psychological wellbeing and social life positive progress. However, the lack of intervention in the financial dimension of the burden of care in the study may be the reason for no difference between the groups.

The factor that differentiates this research from other studies in the literature and provides a positive effect on many aspects of the research may be related to the fact that the program applied to caregivers is supported not only by the group trainings given in the hospital but also by the home visits and telephone conversations provided outside of the clinical setting as well as by having a multidisciplinary team.

This study has several limitations. First, no scale was used to determine the patient's quality of life for the different types of dementia, and data were collected by the scale used only on patients with Alzheimer's disease. Second, the study duration and recurrence measurements were limited. There could be an improvement in most outcomes as the post-test was performed immediately after the 16-week trial. Thus, had the study period been extended, the results could have been different. Finally, some caregivers could not attend the group training because they could not leave their patients alone at home. This resulted in higher home visits and telephone interactions than planned; this intervention also limited the interaction of caregivers with each other.

conclusion; In this study reveals that multicomponent and multidisciplinary interventions, education, and counseling programs have positive impact on caregivers' distress, quality of life, depression, and anxiety. We think that the results of the patients' quality of life and neuropsychiatric symptom severity are clinically but not statistically significant. This is a positive development for a disease without cure. In addition, regular home visits could potentially improve patients' and caregivers' outcomes. Thus, this study recommends using the program for nurses working with dementia patients and their caregivers. Regular and interdisciplinary training and counseling programs should be organized for caregivers, and their efficacy should be assessed. Furthermore, this study highlights the need to add dementia care education to the curriculum for nurses, based on the application of the program to home healthcare providers. Overall, the use of this program for regular home visits by nurses working in primary care units is recommended.

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#### REFERENCES

- World Health Organization. Risk reduction of cognitive decline and dementia: WHO guidelines. 2019. [Internet] Available from: https://www.who.int/ mental\_health/neurology/dementia/en. Accessed: 23.5.2019.
- Alzheimer's Association. World Alzheimer Report. The Global Impact of Dementia. 2015. [Internet] Available from: https://www.alz.co.uk/research/ WorldAlzheimerReport2015.pdf. Accessed:22.5.2017.
- Akyar İ. Nursing Care of demented patient and care models. Hacettepe University Journal of Nursing Faculty 2011;18(2):79-88. (in Turkish).
- Mavioğlu H. Alzheimer Disease. In Tanrıdağ O. (Eds.), Behavioral Neurology. Nobel Medical Bookstores. Istanbul, Turkey 2015, pp:145-72. (in Turkish).
- 5. Özmen D. Examples of the evidence-based applications about subspecialties areas in public health nursing. Turkiye Klinikleri Journal of Public Health Nursing-Special Topics 2017;3(1):29-38. (in Turkish).
- Zwaanswijk M, Peeters JM, Van Beek AP, et al. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. The Open Nursing Journal 2013;(7):6-13. (PMID:23346266).
- Dickinson C, Dow J, Gibson G, et al. Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews. International Psychogeriatrics 2017;29(1):31-43. (PMID:27666669).
- Söylemez BA, Küçükgüçlü Ö, Buckwalter KC. Application of the progressively lowered stress threshold model with community-based caregivers: a randomized controlled trial. Journal of Gerontological Nursing 2016;42(7):44-54 (PMID:27064606).
- Lök N, Bademli K. Pilot testing of the "First You Should Get Stronger" program among caregivers of older adults with dementia. Archives of Gerontology and Geriatrics 2017;(68):84-9. (PMID:27689315).
- Martín-Carrasco M, Martín MF, Valero CP, et al. Effectiveness of a psychoeducational intervention program in the reduction of caregiver burden in Alzheimer's disease patients' caregivers. International Journal of Geriatric Psychiatry: A Journal of the Psychiatry of Late Life and Allied Sciences 2009;24(5):489–99. (PMID:18949763).
- 11. Chien WT, Lee IY. Randomized controlled trial of a dementia care programme for families of

home-resided older people with dementia. Journal of Advanced Nursing 2011;67(4):774-87. (PMID:21198803).

- Akpınar B, Küçükgüçlü Ö. The Validity and Reliability of the Turkish version of the Quality of life scale for patients with Alzheimer's Disease (Qol-AD). Journal of Neurological Sciences 2012;29(3):554-65. (in Turkish).
- Akça Kalem S, Hanagası H, Cummings J, et al. Validation study of the Turkish translation of the Neuropsychiatric Inventory (NPI). 21st International Conference of Alzheimer's Disease International, Sept. 28-Oct. 1, 2005 İstanbul, Turkey. Abstract Book Poster 47.
- Kocyigit H. Reliability and validity of the Turkish version of short form-36 (SF-36): a study in a group of patients will rheumatic diseases. Turk J Drugs Ther 1999;(12):102-6.
- 15. Hisli N. The validity and reliability of the Beck Depression Inventory among university students. Turkish Journal of Psychology 1989;7(23):3-13.
- 16. Ulusoy M, Sahin NH, Erkmen H. The Beck Anxiety Inventory: psychometric properties. Journal of Cognitive Psychotherapy 1998;12(2):163-72.
- 17. İnci FH. Validity and reliability of the Burden Interview and its Adaptation to Turkish. Journal of Ataturk University Nursing School 2008;11(4):85-95. (in Turkish).
- Koivisto AM, Hallikainen I, Välimäki T, et al. Early psychosocial intervention does not delay institutionalization in persons with mild Alzheimer disease and has impact on neither disease progression nor caregivers' well-being: ALSOVA 3-year follow-up. International Journal of Geriatric Psychiatry 2016;31(3):273-83. (PMID:26177825).
- 19. Dias A, Dewey ME, D'Souza J, et al. The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. Brayne C, ed. PLoS ONE 2008;3(6):e2333. (PMID:18523642).
- 20. Au A, Li S, Lee K, et al. The Coping with Caregiving Group Program for Chinese caregivers of patients with Alzheimer's disease in Hong Kong. Patient Education and Counseling 2010;78(2):256-60. (PMID:19619974).
- 21. Kuo LM, Huang HL, Liang J, et al. A randomized controlled trial of a home-based training programme to decrease depression in family caregivers of persons with dementia. Journal of Advanced Nursing 2017;73(3):585-98. (PMID:27653753).



- 22. Akkerman RL, Ostwald SK. Reducing anxiety in Alzheimer's disease family caregivers: the effectiveness of a nine-week cognitive-behavioral intervention. American Journal of Alzheimer's Disease & Other Dementias® 2004;19(2):117-23. (PMID:15106393).
- 23. Santos RL, Sousa MF, Simões-Neto JP, et al. Caregivers' quality of life in mild and moderate dementia.

Arquivos de Neuro-psiquiatria 2014;72(12):931-7. (PMID:25517642).

24. Rotrou J, Cantegreil I, Faucounau V, et al. Do patients diagnosed with Alzheimer's disease benefit from a psycho-educational programme for family caregivers? A randomised controlled study. International Journal of Geriatric Psychiatry 2011;26(8):833-42. (PMID:20922772).