

Impact of care conditions on the caregiver's quality of life in cases with Alzheimer's disease

Alzheimer hastalarında bakım koşullarının bakım verenin yaşam kalitesine etkisi

Nilgün Çınar¹, Şevki Şahin¹, Miruna Florentina Ateş¹, Sibel Karşıdağ¹
¹Maltepe University, Faculty of Medicine, Department of Neurology, Istanbul, Turkey

İletişim: Miruna Florentina Ateş
 Maltepe University, Faculty of Medicine, Department of Neurology,
 Istanbul, Turkey
 e-mail: miruna.ates@gmail.com

SUMMARY

Aim: The quality of life (QoL) of caregivers of Alzheimer's Disease (AD) patients shows individual variability. In this study, we aimed to demonstrate the variability of caregiver burden under differing cases of AD care conditions.

Materials and Methods: In this cross-sectional study, 321 AD caregivers were selected. The primary caregivers of the patient - who were volunteers in our study - are divided into three groups as; Group I: home care (n:111), Group II: day-care center (n:99), Group III: nursing home care (n:111). Patients were classified according to the clinical dementia rating scale (CDR) and evaluated by and Cohen-Mansfield Agitation Inventory (CMAI). Beck anxiety scale (BAS), Beck depression scale (BDS), World Health Organization Quality of Life Assessment short version (WHOQOL-BREF), Zarit Caregiver Burden Interview (ZCBI) and a sociodemographic questionnaire were applied to all caregivers.

Results: According to average age, group III was significantly older than others. There was no statistically significant difference between the groups in terms of duration of patient care. BDS was significantly higher in group III. WHOQOL-BREF score was significantly lower in group III and CMAI score was significantly higher in group III. There was no statistically significant difference between the groups in terms of ZCBI.

Conclusion: Our results revealed that day-care centers play a meaningful role in reducing the stress of caregivers and increasing their QoL. Low-income, chronic diseases of the caregivers, and aggressiveness their patients are the most important factors affecting the caregiver's QoL.

Keywords: Alzheimer's, burden, caring, quality of life

ÖZET

Amaç: Alzheimer Hastalığı (AH) bakımverenlerinin yaşam kalitesi (YK) bireysel değişkenlik göstermektedir. Bu çalışmada, bakım koşulları farklı AH olgularında bakımveren yükünün değişkenliğini göstermeyi amaçladık.

Materyal ve Metodlar: Kesitsel tipteki bu çalışmada 321 AH bakımvereni seçildi. Çalışmamızda gönüllü olan hastanın birincil bakımverenleri üç gruba ayrılmıştır; Grup I: evde bakım (n: 111), Grup II: gündüz bakım merkezi (n: 99), Grup III: huzurevi (n: 111). Hastalar Klinik demans derecelendirme ölçeği (KDDÖ)'ne göre sınıflandırıldı ve Cohen-Mansfield Ajitasyon İnanteri (CMAI) ile değerlendirildi. Beck anksiyete ölçeği (BAÖ), Beck depresyon ölçeği (BDÖ), Dünya Sağlık Örgütü-Yaşam Kalitesi Değerlendirmesi-kısa versiyonu (WHOQOL-BREF), Zarit Bakım verme yükü ölçeği (ZBVYÖ) ve sosyodemografik bir anket tüm bakımverenlere uygulandı.

Bulgular: Ortalama yaşa göre, grup III diğerlerinden anlamlı olarak daha yaşlıydı. Gruplar arasında hasta bakım süresi açısından istatistiksel olarak anlamlı fark yoktu. BDÖ grup III'de anlamlı olarak yüksekti. WHOQOL-BREF skoru grup III'de anlamlı olarak daha düşük ve CMAI skoru grup III'de anlamlı olarak daha yüksekti. Bakım yükü puanları açısından gruplar arasında istatistiksel olarak anlamlı fark yoktu.

Sonuç: Sonuçlarımız, gündüz bakım merkezlerinin bakımverenlerin stresini azaltmada ve yaşam kalitesini arttırmada anlamlı bir rol oynadığını ortaya koymuştur. Bakıcıların düşük geliri, kronik hastalıkları olması ve hastalarının ağırlıklılığı, bakımverenin yaşam kalitesini etkileyen en önemli faktörlerdir.

Anahtar kelimeler: Alzheimer, bakım, yaşam kalitesi, yük

INTRODUCTION

Alzheimer's disease (AD) is the most common type of dementia and is responsible for 60–80% of all cases. Caregiver burden is an important problem for caring patients. Many studies have shown that 60% of caregivers suffer from intense burden (1,2). AD care is a long-term state and associated with psychological and financial burden. In most cases care is usually provided by family members such as daughters and/or daughters-in-law in Turkey (2,3). The quality of life (QoL) of caregivers is considered a multidimensional and complex construct, thus it must be carefully evaluated in all aspects (4). We aimed to determine the factors which affect QoL of caregivers providing care to their patients under differing care conditions - including day-care centre, home care and nursing home. In order to evaluate the QoL of caregivers, their psychiatric and socio-economics conditions were considered.

MATERIALS AND METHODS

Study Design

Participants were selected from caregivers of the AD patients in a current cross-sectional randomized study. A total of 321 caregivers and their patients were included in the study. The caregivers were gathered in three groups (Group I: Caregivers of patients cared for entirely at home, Group II: Caregivers of patients staying at a day-care centre for 5 hours 3 times a week, Group III: Caregivers of patients entirely cared for at a nursing home). Cognitive and behavioural problems of the patients and burden, psychological health status, income, the degree of relationship, hours of care and QoL of their caregivers were evaluated. All caregivers provided informed consent.

Characteristics of Caregivers

Caregivers of the three groups were selected only from family members of AD cases. A demographic questionnaire form designed by us according to previous studies (5,6) including age, gender, education, employment status, occupation, marital status, income, number of children, number of people living at home, existence of chronic disease, degree of relatedness to patient, the presence of others to provide assistance and the duration of care. Beck anxiety scale (BAS), Beck depression scale (BDS), Zarit caregiver burden interview (ZCBI) and World Health Organization Quality of Life Assessment short version (WHOQOL-BREF) were applied to all caregivers (7,8,9,10,11,12,13). The ZCBI is a 18-item instrument that rates caregiving tasks based on difficulty (1= not difficult, 5= extremely

difficult). The points of 18 items are calculated (range, 18-90; higher scores indicate greater caregiver burden). Caregivers were divided into three groups according to their income level as follows: income lower than their expenses, income equal to their expenses and income greater than expenses (7,8).

According to marital status, caregivers were classified as married or single. Degree of relationships was recorded. It was determined whether or not there were any care assistants, and whether the same bedroom was shared with the patient.

WHOQOL-BREF consists of 26 questions about QoL. The Turkish validity and reliability study of the scale was made by Eser et al. The scale includes 4 areas, physical health, mental health, social relations and environmental areas. Each area of WHOQOL-BREF is calculated over 20 points. A high score obtained from the scale indicates a good QoL (13).

Characteristics of Patients

Severity of dementia was classified according to clinical dementia rating (CDR) scale and cases with grade I-II CDR were included in the study (14).

A questionnaire that included age, gender, nutritional status (oral or percutaneous enteral gastrostomy), number of hospitalizations per year, and the presence of other diseases were filled in by caregivers. In addition, psychological symptoms (eg, aggressivity, hallucinations, mood disorder) were evaluated with the Cohen-Mansfield Agitation Inventory (CMAI) (15,16).

Statistical Analyses

The overall data were analyzed with SPSS (Statistical Package for the Social Science) 16.0 for Windows. All parametric data were calculated using standard descriptive statistics.

The Student's t-test was used for comparison of two groups and one-way ANOVA was used for comparison of three groups with a normal distribution, followed by least significant difference post hoc tests. Pearson's correlation analyses were conducted to examine the associations between the other parametric factors and caregiver burden. In addition, a multiple linear regression model was used to analyze the relationship among parameters. Statistical difference is indicated as $p < 0.05$.

RESULTS

The mean age of caregivers were as follows 52±11 years, 64±12 years, 53±15 years; female/male ratio 68/32%, 56/44%, 60/40% for Group I (n:111, home care), Group II (n:99 day-care center) and Group III (n:111 nursing home) respectively. According to age, group III was significantly older (p=0.001). Female caregiver's ratio was 76% and male caregiver's ratio 24% of the group total. There were no statistically significant differences between the groups in terms of gender.

Mean caring duration was 5.6±7 years. There was no significant difference among the groups. The degree of relationship was as follow; 22% spouses, 46% daughters, 17% sons, 3% daughters-in-law, 2% grandchildren, 6% siblings and 2% others. The spouses were 74% wives and 21% husbands.

BDS score was significantly higher and all sub-domains of the WHOQOL-BREF scale were significantly lower in group III. CMAI score of patients was significantly higher in group III. There was no statistically significant difference between the groups in terms of ZCBI. [Table 1]. A correlation was found between ZCBI and the environmental domain of WHOQOL-BREF, BAS, BDS, CMAI scores. [Table 2]

Linear regression analyses was calculated to predict WHOQOL-BREF score based on their BAS, BDS, CMAI, and ZCBI scores. A significant regression equation was found (F (4,68)=7,364, p<0.0001) with an R2 of 0,26. There was no significant correlation between ZCBI and the number of hospitalizations per year and other chronic diseases of the patients.

Education level of caregivers is as follows; 1% uneducated, 11% primary school, 9% secondary school, 32% high school and 46% university. There was no statistically significant correlation between education level and BDS, BAS, ZCBI, and sub-parameters of WHOQOL-BREF scale.

No significant difference was found between income and BDS, ZCBI, WHOQOL-BREF scale. Only the BAS score was found to be significantly higher in the low income group (p=0,01)

Among single and married caregivers, the score of ZCBI was 52.6±17 and 43.2±13 respectively (p=0.01). However, there were no difference in terms of BDS, BAS, WHOQOL-BREF scale in both groups.

There was no difference between BDS, BAS, ZCBI and WHOQOL-BREF according to degree of relatedness, gender and care duration in caregivers. When QoL is compared according to gender, WHOQOL-BREF scores were 17.9±3 in female partners and 22.6±5 in male partners (p=0.04).

The existence of other care assistance did not statistically affect the scores of BDS, BAS, ZCBI and WHOQOL-BREF. When caregivers who are sharing the same bedroom with a patient are compared to those who are not, BDS and BAS were found to be significantly higher (BDS: 26±17/ 15±11 (p=0.01); BAS: 25±15 / 14±10 (p=0.02) respectively). Environmental subdomain scores of WHOQOL-BREF were significantly lower in caregivers sharing the same room with a patient [21±7/ 26±4 (p=0.02)].

The BAS scores of caregivers with chronic diseases were significantly higher than for those without chronic diseases (21.7±12, 14.5±11 p=0.01).

No significant relationship was found between the nutritional status of the patient and BDS, BAS, ZCBI, WHOQOL-BREFscores.

Table 1. The results of caregivers. All values are shown as mean and standard deviation. P<0,05 was accepted as statistically meaningful [BAS: Beck anxiety scale, BDS: Beck depression scale, WHOQOL-BREF: World Health Organization Quality of Life Assessment short version, ZCBI: Zarit caregiver burden interview, CMAI: Cohen-Mansfield Agitation Inventory].

Groups	Age	BAS	BDS	WHOQOL-BREF Physical health	WHOQOL-BREF Psychological	WHOQOL-BREF Social relationships	WHOQOL-Environmental	ZCBI	CMAI
Group 1 Home Care (n=111)	52±11	15±10	13±9	21±3	20±4	9±3	28±5	45±16	50±31
Group 2 Day Care Center (n=99)	64±12	15±11	11±7	21±2	19±2	9±2	26±4	51±17	43±16
Group 3 Nursing Home (n=111)	53±15	19±15	27±16	17±3	15±4	7±2	20±4	52±15	71±42
p	0.001	0.4	<0.001	<0.0001	<0.0001	0.003	<0.0001	0.2	0.01

Table 2. Correlation between subdomains of WHOQOL-BREF, Zarit caregiver burden interview (ZCBI) and the other scales. [BAS: Beck anxiety scale, BDS: Beck depression scale, WHOQOL-BREF: World Health Organization Quality of Life Assessment short version, CMAI: Cohen-Mansfield Agitation Inventory].

ZCBI	BAS	BDS	CMAI score	WHOQOL BREF Environmental	WHOQOL BREF Physical Health	WHOQOL BREF Physiological	WHOQOL BREF Social Relationships
BAS	0.5 (p<0,0001)						
BDS	0.4 (p<0,0001)	0.5 (p<0.0001)					
CMAI score	0.3 (p<0,0001)	0.4 (p<0.0001)	0.6 (p<0.0001)				
WHOOL BREF Environmental	-0.2 (p=0.02)	-0.2 (p=0.02)	-0.5 (p<0,0001)	-0.1 (p=0.1)			
WHOOL BREF Physical Health	-0.1 (p=0.1)	-0.2 (p=0.06)	-0.5 (p<0.0001)	-0.2 (p=0.01)	0.7 (p<0.0001)		
WHOOL BREF Psychological	-0.1 (p=0.2)	-0.1 (p=0.6)	-0.4 (p<0.0001)	-0.1 (p=0.1)	0.7 (p<0.0001)	0.7 (p<0.0001)	
WHOOL BREF Social Relationships	-0.1 (p=0.09)	-0.1 (p=0.1)	-0.3 (p<0.0001)	-0.2 (p=0.08)	0.6 (p<0.0001)	0.7 (p<0.0001)	0.7 (p<0.0001)

DISCUSSION

Alzheimer's disease extends over a long period of time. The QoL of the caregivers may be affected by the location where the patient is being cared for (17). Many studies showed that female gender, low level of education, living with the patient, depression, social isolation, and financial problems may increase caregiver burden and affect the QoL negatively (18,19,20). In our study, there was a significant difference among groups in terms of QoL of caregivers. Although care burden was high in all of the groups, there were no differences between the groups (mean caregiver burden score 49.5 ± 16). In most studies, it was reported that caregivers for chronic medical conditions are generally women (20,21,22). In some of the studies, the ratio of female caregivers in Turkey has been reported as 67% to 86% (23). Moreover, Altun et al suggested that 78% of caregivers were female, of which 34% were wives (7). In our study the female ratio was found to be 76% and the most frequent caregivers were found to be daughters, followed by wives. In addition, we found that female partners' QoL were worse than those of male partners. This is consistent with the results of previous studies.

The mean age of caregivers has been reported as being between 58 and 60 (24). In our study the age range of caregivers' was from 52-76 years old and consisted of mostly middle-aged people as has been reported in previous studies.

Anxiety is a main challenge that is faced by family caregivers of patients with AD (1). In our study it was found that caregivers who have chronic diseases are more anxious despite no significant change being found in the care burden between groups.

The rates of depression among the caregivers of patients staying in a nursing home were high in our study. There were also higher rates of agitation in patients living in the nursing home. Many studies have examined the relationship between agitation and living in a nursing home. While some found a positive correlation between the presence of agitation and living in a nursing home, others did not find a statistically significant correlation between the two variables (25).

Kazhungil et al showed that negative factors in caregiver burden are associated with low income and presence of chronic disease (26). In our study, anxiety scores were found significantly higher in the low income group and in caregivers with chronic diseases.

Rodríguez-González et al showed that the factors which contribute most to caregiver burden are lack of private time for him or herself, number of care hours, and psychological health of caregivers (27). The results of our study reveal that the caregivers' lack of a private room and to be alone (single, divorced, widowed) had a negative impact on the QoL.

Some positive solutions such as daytime care centers and welfare services may improve caregivers' mood, coping, self-efficacy and QoL. Various psychosocial supports to patients and caregivers in these centers reduce the stress of caregivers (28). In our study, aggression was found to be lower in patients staying in day care centers and that depression was found to be lower in their caregivers. An increase in such centers will improve the QoL of patients and caregivers.

CONCLUSION

In this study, we evaluated the factors affecting the quality of life of caregivers of Alzheimer's patients cared for in three differing locations. Our results revealed that daycare centers play a meaningful role in reducing the stress of caregivers and increasing their QoL. Low-income and chronic illnesses of the caregivers and aggressiveness of patients are the most important factors affecting the caregiver's QoL. It is also as important to support caregivers and reduce their distress as it is to improve the care conditions of patients. It is necessary to arrange educational and social programs for family members of AD patients. Further multicenter studies on improving QoL and more assessment of caregiver requirements are needed.

REFERENCES

1. Liu S, Li C, Shi Z, Wang X, Zhou Y, Liu S, et al. Caregiver burden and prevalence of depression, anxiety and sleep disturbances in Alzheimer's disease caregivers in China. *J Clin Nurs*. 2017;26:1291-300.
2. Şahin ZA, Polat H, Ergüney S. Kemoterapi alan hastalara bakım verenlerin bakım verme yüklerinin belirlenmesi. *Ankara Üniversitesi Hemşirelik Yüksek Okulu Dergisi*. 2009;12: 1-9.
3. Tel H, Demirkol D, Kara S, Aydın D. Care Burden and Quality of Life Among the Caregivers of Patients with COPD. *Türk Toraks Derg*. 2012;13:87-92.
4. Römhild J, Fleischer S, Meyer G, Stephan A, Zwakhlen S, Leino-Kilpi H, et al. Inter-rater agreement of the Quality of Life-Alzheimer's Disease (QoL-AD) self rating and proxy rating scale: secondary analysis of Right Time Place Care data. *Health Qual Life Outcomes*.

- 2018;28:131.
5. Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JH, Francke AL. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Open Nurs J.* 2013;7:6-13.
 6. Dimakopoulou E, Sakka P, Efthymiou AC, Karpathiou N, Karydaki M. Evaluating the Needs of Dementia Patients' Caregivers in Greece: A Questionnaire Survey. *IJCS.* 2015;8:274-80.
 7. Zarit SH, Reever KE, Bach-Peterson J. Relatives of The Impaired Elderly: Correlates of Feelings of Burden. *Gerontologist.* 1980;20:649-55.
 8. İnci FH, Erdem M. Bakım verme yükü ölçeğinin Türkçe'ye uyarlanması geçerlilik ve güvenilirliği. *Atatürk Üniversitesi Hemşirelik Yüksekokulu Dergisi.* 2008;11:4.
 9. Beck AT, Epstein N, Brown G, Steer RA. An inventory for measuring clinical anxiety: psychometric properties. *J Consult Clin Psychol.* 1988;56:893-97.
 10. Ulusoy M, Şahin N, Erkmén H. Turkish version of the Beck Anxiety Inventory. *J.Cogn Psychother.* 1998;12:163-72.
 11. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry.* 1961;4:561-71.
 12. Hisli N. Beck Depresyon Envanterinin üniversite öğrencileri için geçerliği, güvenilirliği. *Psikoloji Dergisi.* 1989;7:3-13.
 13. Eser E, Fidnner H, Fidaner C, Eser SY, Elbi H, Göker E. WHOQOL-100 ve WHOQOL-BREF'in psikometrik özellikleri. *Psikiyatri Psikoloji Psikofarmakoloji (3P) Dergisi.* 1999;7:23-40.
 14. Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. *Br J Psychiatry.* 1982;140:566-72.
 15. Özel Kizil ET, Bastug G, Erdogan S, Sakarya D. Psychometric properties of the Turkish version of Cohen-Mansfield Agitation Inventory in patients with dementia. *Turk Geriatri Derg.* 2012;15:24-29.
 16. Cohen-Mansfield J, Marx MS, Rosenthal AS. A description of agitation in a nursing home. *J Gerontol.* 1989;44:77-84.
 17. Yu H, Wang X, He R, Liang R, Zhou L. Measuring the Caregiver Burden of Caring for Community-Residing People with Alzheimer's Disease. *PLoS One.* 2015;8:1-13.
 18. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA.* 2014;12:1052-60.
 19. Zucchella C, Bartolo M, Bernini S, Picascia M, Sinforiani E. Quality of life in Alzheimer disease: a comparison of patients' and caregivers' points of view. *Alzheimer Dis Assoc Disord.* 2015;29:50-54.
 20. Prince MJ. The 10/66 dementia research group - 10 years on. *Indian J Psychiatry.* 2009;51:8-15.
 21. Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family -caregivers of people with mental illnesses. *World J Psychiatry.* 2016;22:7-17.
 22. Baker KL, Robertson N. Coping with caring for someone with dementia: reviewing the literature about men. *Aging Ment Health.* 2008;12:413-22.
 23. Akyar İ, Akdemir N. Alzheimer Hastalarına Bakım Verenlerin Yaşadıkları Güçlükler. *Hacettepe Hemşirelik Dergisi.* 2009;16:32-49.
 24. Moscoso MA, Marques RCG, Ribeiz SRI, Dos Santos L, Bezerra DM, Jacob Filho W, et al. Profile of caregivers of Alzheimer's disease patients attended at a reference center for cognitive disorders. *Dement Neuropsychol.* 2007;1:412-17.
 25. Miller EA, Schneider LS, Rosenheck RA. Predictors of nursing home admission among Alzheimer's disease patients with psychosis and/or agitation. *Int Psychogeriatr.* 2011;23:44-53
 26. Kazhungil F, Velayudhan R, Kumar M, Thazhe Mangool R. A comparative study of caregiver burden in late-onset depression and Alzheimer's disease. *Psychogeriatrics.* 2016;16:209-15.
 27. Rodríguez-González AM, Rodríguez-Míguez E, Duarte-Pérez A, Díaz-Sanisidro E, Barbosa-Álvarez Á, Clavería A; Grupo Zarit. Cross-sectional study of informal caregiver burden and the determinants related to the care of dependent persons. *Aten Primaria.* 2017;49:156-65.
 28. Large S, Slinger R. Grief in caregivers of persons with Alzheimer's disease and related dementia: a qualitative synthesis. *Dementia (London).* 2015;14:164-83.