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RESEARCH

THE EFFECT OF AGITATION ON CAREGIVERS' BURDEN IN PATIENTS WITH DEMENTIA

ABSTRACT

Introduction: The purpose of this study was to examine the effect of agitation on caregiver relatives' subjective burden together with other possible factors such as depressive symptoms, cognitive functions, duration of dementia, and caregivers' age, education and gender.

Materials and Method: The participants were 49 patients with dementia (mean age: 76.5; SD: 5.6) and their caregivers. Standardized Mini Mental Test and Cornell Scale for Depression in Dementia were administered to the patient. Cohen-Mansfield Agitation Inventory, Informant Questionnaire of Cognitive Decline in the Elderly and Zarit Burden Scale were administered to the caregivers. Linear regression analysis was used to examine the effects of the variables on caregiver burden.

Results: There was neither a significant difference between gender and type of caregiver in terms of Zarit Burden Scale points, nor a significant correlation between Zarit Burden Scale scores and Standardized Mini Mental Test, Cornell Scale for Depression in Dementia, age and education of the patient, education of the caregiver or duration of dementia. Significant correlations between Zarit Burden Scale scores and caregivers' age, Informant Questionnaire of Cognitive Decline in the Elderly and Cohen-Mansfield Agitation Inventory scores were found. Linear regression analysis showed a relationship only between agitation and caregiver burden.

Conclusion: Patients' agitation frequency which was assessed by Cohen-Mansfield Agitation Inventory was the basic factor in determining subjective caregiving. In addition to psychopharmacological treatment, psychosocial interventions for caregivers are effective. In our country, daycare and homecare services, as well as supportive and educative psychosocial programs including interventions for agitation, should be improved.

Key Words: Dementia; Caregivers; Psychomotor Agitation.



ARAŞTIRMA

DEMANS HASTALARINDA AJİTASYONUN BAKIM VEREN YÜKÜNE ETKİSİ

Öz

Giriş: Bu çalışmanın amacı demans hastalarına bakım veren yakınlarında ajitasyonun öznel bakım veren yüküne etkisinin depresif belirtiler, bilişsel işlevler, demans süresi, bakım verenin yaşı, eğitimi, cinsiyeti gibi diğer etmenlerle birlikte araştırılmasıdır.

Gereç ve Yöntem: Araştırmaya toplam 49 demans hastası (Ort. yaş: 76.5; Ss: 5.6) ve 49 bakım veren katılmıştır. Verilerin toplanmasında, hastalara Standardize Mini Mental Test ve Cornell Demans Depresyon Ölçeği, bakım verenlere ise Cohen-Mansfield Ajitasyon Envanteri, Bilişsel Kayıp için Bilgilendiriciye Uygulanan Anket ve Zarit Bakıcı Yükü Ölçeği uygulanmıştır.

Bulgular: Bakım verenin cinsiyeti ve yakınlık türü ile Zarit Bakıcı Yükü Ölçeği puanları açısından istatistiksel olarak anlamlı fark bulunmadığı gibi Standardize Mini Mental Test ve Cornell Demans Depresyon Ölçeği puanları, bakım verenin eğitim süresi, hastanın yaşı, eğitim süresi ve hastalık süresi ile de anlamlı korelasyon bulunmamıştır. Zarit Bakıcı Yükü Ölçeği ile Cohen-Mansfield Ajitasyon Envanteri puanı, bakım veren yaşı ve Bilişsel Kayıp için Bilgilendiriciye Uygulanan Anket puanı arasında anlamlı korelasyon saptanmıştır. Lineer regresyon analizinde ise bakıcı yükünün yalnızca ajitasyon puanı ile ilişkili olduğu bulunmuştur.

Sonuç: Bu çalışmada elde edilen sonuçlar demans hastalarında Cohen-Mansfield Ajitasyon Envanteri ile değerlendirilen ajitasyon sıklığının öznel bakım veren yükünü belirleyen temel faktör olduğuna işaret etmektedir. Bakım verme işinin kolaylaştırılması için psikofarmakolojik tedavilerin yanı sıra bakım verenlere yönelik psikososyal girişimler de etkili olmaktadır. Ülkemizde ajitasyona yönelik müdahaleler içeren evde ve gündüz bakım hizmetlerinin, bakım verenlere yönelik psikososyal destek ve bilgilendirme programlarının yaygınlaştırılması gereklidir.

Anahtar Sözcükler: Demans; Bakım Verenler; Psikomotor Ajitasyon.

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INTRODUCTION

Dementia is a syndrome characterized by progressive deterioration in many cognitive functions, such as praxia, gnosis, visual-spatial and executive functions, and in daily living activities. As well as the cognitive symptoms, a variety of neuropsychiatric symptoms such as depression, anxiety, delusions, hallucinations, changes in sleep and appetite patterns and agitation appear in the course of dementia. Patients with dementia need long term care as a consequence of these symptoms. These three symptom clusters have been presented as the most important factors associated with caregiver burden (1).

Caregiver burden is a concept which describes physical, emotional and financial consequences of care giving. Two types of caregiver burden have been identified: subjective and objective. Subjective burden is a state that can be described by caregivers and assessed with various inventories. This concept involves the behavioral and emotional reactions of a person to the caregiving experience. On the other hand, objective burden is based on objective criteria such as the time and money spent on caregiving. Subjective caregiver burden is thought to be especially important in the maintenance of successful rehabilitation and care (2). Since neuropsychiatric symptoms are treatable, it is important to manage them in order to decrease caregiver burden. Neuropsychiatric symptoms seen in patients with dementia were found to be the main predictors of the caregiver burden in some studies (1, 3). Among the neuropsychiatric symptoms, agitation was reported to be the most important cause of caregiver burden (4).

Furthermore, some studies have found that caregiver burden decreases if the agitation is treated (5). Additionally, the clinical course of dementia and nursing home placement can be affected by caregiver burden (6). Results of previous studies suggest that caregiver burden and/or stress/burnout experienced by caregivers can differ according to culture (3). Despite the paucity of statistical data, it would appear that most patients with dementia are given care at home by their relatives because of the traditional family structure in our country, which has low nursing home placement rates (7).

Caregiver burden and burnout levels of caregivers of dementia patients have been investigated in previous studies in Turkey. One of these studies founded that anxiety level, phobias and duration of care were correlated with the burden of caregivers of Alzheimer patients (n=23) (8).

There has been no published research in our country about the effect of agitation on caregiver burden for dementia patients. Therefore, this study aimed to investigate the effect of

agitation on caregiver burden, along with other possible causes of burden such as depressive symptoms, cognitive functions, duration and severity of dementia and socio-demographic data of the caregivers.

MATERIALS AND METHOD

Study Sample

The study sample consisted of 49 patients who were diagnosed with dementia according to the Diagnostic and Statistical Manual of Mental Disorders-Text Revised Edition (DSM-IV-TR) criteria, and their caregivers (9). Patients who did not have a caregiver or refused to participate in the study were excluded. Caregivers who had not known the patients for at least 10 years were also excluded from the study. The present study was approved by the ethics committee of Ankara University and signed informed consents were taken from the caregivers. The Standardized Mini Mental Test (SMMT) and the Cornell Scale for Depression in Dementia (CSDD) were administered to the patients. The Cohen-Mansfield Agitation Inventory (CMAI), The Informant Questionnaire of Cognitive Decline in the Elderly (IQ-CODE), Functional Activities Questionnaire (FAQ) and the Zarit Burden Scale (ZBS) were administered to the caregivers. Details of these instruments are described below.

The Standardized Mini Mental Test (SMMT) consists of 30 items that evaluate cognitive functions such as orientation, registration, recall, attention, calculation and language. Lower scores indicate cognitive deterioration. It is widely used because of its short application time. The Turkish form of the SMMT has been shown to be valid and reliable by Gungen et al. (10).

The Cornell Scale for Depression in Dementia (CSDD) was specifically developed to assess major depression in patients with dementia. It is completed by the clinician via interviews with patients and their caregivers. Five subgroups (mood related signs, behavioral disturbances, physical findings, cyclic functions, ideational disturbances) are assessed on 19 items. Each item is scored between 0 and 2. Scores above 7 are highly suggestive for depression. The Turkish adaptation of the CSDD was developed by Amuk et al. (11).

The Informant Questionnaire of Cognitive Decline in the Elderly (IQ-CODE) consists of 26 items and is useful for evaluation of disturbances in cognitive functions and daily living activities. It is completed by the patient's caregiver. Informants are asked to rate the degree of change over the previous 10 years in 39 aspects of everyday cognitive functioning.



Therefore, “caregiver must have known the patient for at least for 10 years” was accepted as an inclusion criterion. A validity and reliability study of the Turkish version of the IQ-CODE was carried out by Ozel-Kizil et al. (12). The IQ-CODE score equals the sum of the items divided by the number of items. IQCODE scores above 3.4 were found to be predictive of dementia in the adaptation study for the Turkish version (12).

The Functional Activities Questionnaire (FAQ) assesses independence in daily activities and is a widely used screening tool for dementia. It is completed by the administrator via an interview with the patient’s caregiver. The total score is the sum of the individual item scores; higher scores reflect greater dependency. Total scores range from 0-30. The adaptation study of the Turkish form of the scale was carried out by Selekler et al. (13).

The Cohen-Mansfield Agitation Inventory (CMAI) consists of 29 items. It is a seven- point rating scale (1-never and 7- several times an hour) which assesses the frequency of agitation behaviors. It should be completed by a rater during an interview with the caregiver. The total score (29-203) is the sum of individual item scores; higher scores reflect more severe agitation. An adaptation study of the Turkish form of the CMAI was carried out by Ozel-Kizil et al. (14).

The Zarit Burden Scale (ZBS) was developed by Zarit, Reever and Bach-Peterson in 1980 to assess difficulties experienced by caregivers. It uses a five-point Likert scale (never, rarely, sometimes, quite frequently, nearly always) consisting of 22 items and is completed by caregivers. Higher scores reflect more severe burden (15). Two different Turkish adaptation studies have been conducted with this scale. The first was performed by Inci and Erdem (2008) and involved 220 caregivers of elderly people. Internal consistency correlations for the scale were reported as 0.95 and inter-item correlation values were moderate, strong and very strong (between 0.43 and 0.85). The test-retest consistency coefficient was 0.90. Factor analysis yielded only one factor, which explained 53.6% of the total variance (16). The latter study involved 100 caregivers of patients with schizophrenia and was carried out by Ozlu et al. In this study, factor analysis yielded five factors, explaining 61% of the total variance. These factors were “mental irritability and subjective deterioration of living” (items: 2, 3, 10, 11, 12, 17, 19), “nervousness and feeling restricted” (items: 5, 9, 22), “deterioration in social relationships” (items: 6, 13, 18), “economic burden” (items: 15, 20, 21, 7) and “dependency” (items 8, 14). Items 1, 4 and 16 were not included in any factor because of their low factor loadings (17).

Table 1— Sociodemographic Features of The Patients and The Caregivers

	Patients With Dementia (n=49)	Caregivers (n=49)
Age (mean and SD)	76.5±5.6	53±12
Total years of education (mean and SD)	4.7±3.6	8.9±4.7
Gender (F/M)	24/25	36/13

Data Analysis

An independent samples t-test was used to compare ZBS scores of males and females. Pearson correlation tests were used to assess the correlations between ZBS scores and other variables (CMAI scores, age, education of the patient and the caregiver, estimated dementia duration, other scale scores, etc.) In addition, the relationships between factors of the ZBS and CMAI total scores were assessed using Pearson correlation tests. Linear regression analysis was used to evaluate the effects of factors that significantly correlated with ZBS on caregiver burden. All statistical analyses were performed using SPSS 17.0.

RESULTS

Socio-demographic characteristics of the patients and their caregivers are presented in Table 1. 75.5% (n=37) of caregivers were children and 24.5% (n=12) were spouses of the patients. 71.4% (n=35) of patients were diagnosed with dementia due to Alzheimer’s disease. The other diagnoses were: mixed type dementia (n=10, 20.4%), vascular dementia (n=2, 4.1%) and other dementia (n=2, 4%). More than half of the patients had agitation behaviors such as “repetitive sentences and questions”, “negativism” and “general restlessness”. “Biting” was not reported for any of the patients.

Mean scores of the scales which were applied to the patients and caregivers are given in Tables 2 and 3. There were no statistically significant differences between male and female or spouse and child caregivers in terms of ZBS total scores

Table 2— Mean and Standard Deviations of The Scale Scores Applied to The Patients.

	Patients With Dementia (n=49)
SMMT total score	14.7± 6.7
CSDD total score	6.8±6.4

**Table 3**— Mean and Standard Deviations of The Scale Scores Applied to The Caregivers.

	Caregivers (n=49)
IQCODE total score	4.1±0.7
CMAI total score	57.5±27.3
FAQ total score	17.1±11.2
ZBS total score	38.8±21.3

($t=1.29$, $p=0.20$; $t=1.38$, $p=0.17$, respectively). Significant correlations were found between ZBS total scores and the age of the caregiver ($r=-0.42$, $p=0.004$), CMAI scores ($r=0.692$, $p<0.001$), and IQ-CODE scores ($r=0.34$, $p=0.02$). There were no significant correlations between ZBS scores and SMMT scores, CSDD scores, caregiver's education (total years), age of the patient, patient's education (total years) or duration of the illness ($p>0.05$).

According to the linear regression analysis ($b=0.559$, $SE=0.085$, $\beta=0.692$, $t=6.576$, $p<0.001$), ZBS total scores were associated with CMAI total scores. Age of the caregiver and the IQ-Code scores did not enter the model.

There were significant positive correlations between CMAI total scores and "mental irritability and subjective deterioration of the living", "nervousness and feeling restricted", "deterioration in social relationships", and "economic burden" factors ($r=0.59$, $p < 0.001$; $r=0.67$, $p < 0.001$; $r=0.58$, $p<0.001$; $r=0.61$, $p<0.001$, respectively). No significant correlation was found between CMAI total scores and the "dependency" factor ($r=0.23$, $p=0.12$).

DISCUSSION

Results of the present study show that agitation frequency which was assessed by the CMAI in dementia patients is the main factor that affects caregiver burden. Agitation was correlated with all of the sub-components of caregiver burden except dependency. Functional and cognitive status, depressive symptoms, age and gender of the patient, education of the caregiver, duration of the care and the relation of the caregiver to the patient were not found to be associated with caregiver burden. These results are consistent with the results of previous studies that have been carried out in different countries. Victoroff et al. indicated that caregiver burden in patients with dementia was associated with agitation but not with delusions, hallucinations or depressive symptoms (4). A study from China that assessed patients with dementia using the Neuropsychiatric Inventory and their caregivers using the

ZBS also found that caregiver burden was mainly associated with apathy and agitation (18). Follow-up studies performed in recent years yielded similar results. For instance, a multi-center study from Spain, which included 1235 moderate to severe patients with Alzheimer's Disease, indicated that although functional and cognitive status deteriorated significantly at the end of a twelve-month period, caregiver burden decreased with decreased behavioral disturbances (19). A three-year follow-up study from the USA that included 5831 primary caregivers of dementia patients found that 43.9% of the patients were placed in nursing homes, and behavioral disturbance/agitation (aggression, damage to property, repetitive questions and living in the past) was mainly associated with nursing home placement (20).

Although there are a few studies concerning caregiver burden and dementia in our country, interpretation of their results is difficult due to different methodologies. Akyar and Akdemir (21) investigated the difficulties experienced by caregivers of patients with Alzheimer's Disease ($n=50$) and indicated that wandering and fecal incontinence were related to the problems of care. Yilmaz et al. (22) found that depressive symptoms and functional status were related to burnout in caregivers of these patients ($n=44$). Therefore, the present study can be accepted as the first study in Turkey that investigated the effect of agitation on caregiver burden, together with other factors, in a detailed manner.

Daily functioning of the patients which was assessed by FAQ scores seem to be in a wide range in the present study and functional status was not related to caregiver burden. This result may be due to the heterogeneity of the sample in terms of dementia etiology. Therefore, another study consisting of only patients with Alzheimer's Disease would give different results in terms of the relation between functional status and caregiver burden.

A study by Cohen-Mansfield, which included dementia patients in nursing homes ($n=191$), showed that non-aggressive verbal agitation (repetitive sentences and questions, complaining, etc.) was the most frequent behaviour and most disruptive behaviour for the caregivers. However, when the frequency of this behavior was used as a covariate, physically aggressive behaviours were found to be the most disruptive ones (23). In the present study "repetitive sentences and questions" and "complaining" were also found to be the most frequent agitation behaviours in patients with dementia.

Another result of the present study is that the caregiver's gender had no effect on caregiver burden. This issue is controversial. Some of the previous studies pointed out that burden



is higher in female caregivers, and other studies have found no difference in terms of gender. A study by Akpınar et al. (24) compared caregiver burden in males and females and found a higher burden in females. This result was explained by the assumption that females were more likely to express their emotional status than males. On the other hand, Yılmaz et al. (22) found no gender difference in terms of caregiver burden. In our study, most of the caregivers were middle-aged women. In previous studies carried out in Turkey, most of the caregivers of patients with dementia were also female (22, 25). The Turkish validity and reliability study of the Caregiver Burden Inventory included 240 caregivers of patients with dementia and most of them were also female (mean age 53.88 ± 13.31 , 78.3% females, 48.7% were daughters of the patients) (25). These results are parallel to those found in other countries and emphasize that caregiving is mostly carried out by females. Therefore, caregiving issues in females should be taken into account with regard to preventive psychiatric services.

Although it did not enter the final model, there was a negative correlation between the age of the caregiver and the caregiver burden. This result suggests that young caregivers are more in need of maintaining their social interactions and occupations, so burden in the social domain is higher. In the present study, the increase in burden with decreasing age may also be associated with less adequate coping skills of younger people.

Additionally, it is interesting that while no associations were found between objective cognitive performances and caregiver burden, a significant correlation was found between subjective informant ratings of cognitive status evaluated by the caregiver on the IQ-CODE, and caregiver burden. This result is important with regard to the difference between objective cognitive disturbance of the patient and the perception of the caregiver. Caregivers of patients with dementia deal not only with the treatment of their patients but also with neuropsychiatric manifestations that appear as the dementia progresses. Progressive disability, gradual increase in dependency of the patient on the caregiver, and receiving no positive feedback to restore hope are the most disturbing factors for caregivers (3). Treatment in dementia is mostly symptomatic and aims to increase the quality of life of the patient and support their care. Therefore, agitation behaviors which are frequently encountered in dementia patients and are disruptive for caregivers should be taken into account in the treatment process.

As well as psychopharmacological treatments for the patients, psychosocial interventions for the caregivers are also re-

commended. When the difficulty of the caregiving process is taken into account, multidimensional interventions such as psychoeducation, support groups, relaxation techniques, etc. were reported to be more effective than unidimensional treatment options.

Overall, the results of this study suggest that daily care and care at home services should be enhanced and extended in our country, and psychosocial support and information programs for caregivers should be improved.

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