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Effects of Early- and Late-Onset Alzheimer's Disease on Caregiver Burden

Erken ve Geç Başlangıçlı Alzheimer Hastalığının Bakım Veren Yükü Üzerine Etkisi

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Abstract

Introduction: Alzheimer’s disease (AD) is the most common cause of dementia. Early-onset AD (EOAD) occurs when it affects someone under the age of 65, and many people diagnosed are in their 40s and 50s. Many studies in the literature examine the caregiver burden of people with late-onset AH (LOAD), and it is unclear whether the experience of caregiving differs according to the age of onset of AH. Aim: This study aimed to determine whether there is a difference in the caregiver burden of primary informal caregivers of community-dwelling patients with AD according to the age of onset of the disease. Methods: A comparative descriptive study design was used in this study. The sample comprised 109 people with AD (34 EOAD and 75 LOAD) and their caregivers. Sociodemographic characteristic questionnaires, the Caregiver Burden Inventory, the Mini-Mental State Examination, the Neuropsychiatric Inventory, Barthel’s Activities of Daily Living, and the Clinical Dementia Rating Scale were used. Descriptive statistics, t-tests, and chi-square were used to describe and analyze the data. Results: Caregivers of patients with EOAD had significantly higher scores for social burden than caregivers of patients with LOAD (t=3.156, p=0.002). Furthermore, caregivers of patients with EOAD experienced more developmental, physical, and total burden than caregivers of patients with LOAD. However, these differences were not statistically significant (p>0.05). Conclusion: Considering that there will be differences in the caregiver burden of AH according to the age of onset, it is necessary to offer services tailored to the needs of AD caregivers.

Keywords: Alzheimer’s disease, dementia, caregiver burden.

Özet

Giriş: Alzheimer hastalığı (AH), demansın en sık görülen tipidir. Görülme yaşı 65 yaş altındaki bireyleri etkilediğinde erken başlangıçlı AH (EBAH) olarak adlandırılmakta olup tanı konulan birçok kişi 40’lı ve 50’li yaşlarındadır. Literatürdeki birçok çalışma geç başlangıçlı AH (GBAH) olan bireylere bakım verenlerin bakım veren yükünü incelemekte olup bakım verme deneyiminin AH’nin başlangıç yaşına göre farklılık gösterip göstermediğine ilişkin belirsizlik sürmektedir. Amaç: Bu çalışma, toplumda yaşayan AH’li bireylere primer informal bakım verenlerin bakım veren yüklerinde hastalığın başlangıç yaşına göre farklılık olup olmadığının belirlenmesi amacıyla yapılmıştır. Yöntem: Bu çalışmada karşılaştırmalı tanımlayıcı araştırma deseni kullanılmıştır. Araştırmanın örneklemini 109 AH’li birey (34 EBAH ve 75 GBAH) ve bakım verenleri oluşturmaktadır. Veriler; sosyodemografik özellikler formu, Bakım Verenlerin Yükü Envanteri, Mini Mental Durum Testi, Nöropsikiyatrik Envanter, Barthel Günlük Yaşam Aktiviteleri ölçeği ve Klinik Demans Derecelendirme Ölçeği kullanılarak toplanmıştır. Verilerin değerlendirilmesinde tanımlayıcı istatistikler, t test ve ki-kare analizi kullanılmıştır. Bulgular: EBAH’lı bireylere bakım verenlerin sosyal yük puan ortalamalarının GBAH’lı bireylere bakım verenlere göre daha yüksek olduğu bulunmuştur (t=3,156, p=0,002). Ayrıca, EBAH’lı bireylere bakım verenler daha fazla gelişimsel, fiziksel ve toplam yük yaşamaktadır. Ancak istatistiksel olarak anlamlı farklılıklar oluşturmamaktadır (p>0,05). Sonuç: AH’nin başlangıç yaşına göre bakım veren yükünde farklılıklar olacağı göz önünde bulundurularak bakım verenlerin ihtiyaçlarına göre uyarlanmış hizmetlerin sunulması gerekmektedir.

Anahtar kelimeler: Alzheimer hastalığı, demans, bakım veren yükü.

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Introduction

Alzheimer's disease (AD) is the most common type of dementia in older and younger adults. When it affects people aged<65 years, it is called early-onset AD (EOAD), and several people diagnosed with EOAD are in their 40s and 50s.[1,2] EOAD accounts for 30%–40% of early-onset dementia cases.[3] Of the more than 5 million Americans diagnosed with AD, 5% have EOAD.[2]

EOAD is not as prevalent as late-onset AD (LOAD), but it can have a more significant impact than LOAD on patients and their families.[4] The disease process usually progresses faster in EOAD than in LOAD.[5] Patients diagnosed with EOAD experience faster cognitive and functional decline than patients diagnosed with LOAD.[6] It has been reported that attention, verbal fluency, and executive functions are more impaired in patients with EOAD than those in patients with LOAD.[7,8] However, behavioral problems such as delirium, hallucinations, agitation, disinhibition, and abnormal motor behavior have been less frequently observed in patients with EOAD compared with patients with LOAD.[7,9] Furthermore, individuals with EOAD usually play an active role in society. The loss of roles and responsibilities may therefore be greater in people with EOAD than in people with LOAD.[4] In their qualitative study, Dourado et al. (2018) found that caregivers who care for individuals with EOAD are affected psychologically, physically, economically, and socially.[10] They should address specific issues such as difficulties with proper diagnosis, marital problems, family conflicts, (un)employment, financial issues, and child-rearing.[4] Additionally, spouses or relatives caring for people with EOAD may experience social stigma, anxiety, and depression.[11] Therefore, the needs and requirements for support and services for people with EOAD and their caregivers may be different.[10,12]

It is important to address care needs, which are associated with negative results such as poor quality of life,[13,14] neuropsychiatric symptoms,[13,] and earlier nursing home placement.[15] These negative consequences can result in a caregiver burden. Moreover, the caregiver burden has been considered the most important factor that influences caregivers' view of life.[16] Over the past few decades, numerous studies have documented the impact of AD on caregiver burden in LOAD. There are scarce studies that have examined the difference in caregiver burden between caregivers of EOAD and LOAD.[4] Caregivers with LOAD spent more time helping their relatives when their activities of daily living scores were lower and therefore needed more social services than caregivers with EOAD. In addition, although there is no difference in behavioral problems, the burden on caregivers with EOAD is higher, but not statistically different[17] This finding is consistent with the findings of Millenaar et al. (2016).[18] However, the literature states that the behavioral problems of patients with EOAD are greater than those with LOAD, so the mental health of those who care for them is worse,[19] and there is also a greater caregiver burden.[20] In the literature, it remains unclear whether caregiver experience differs according to the onset of AD. To adequately support caregivers, it is important to determine whether the onset of AD affects the caregiver burden.[4] In this context, this study aimed to determine whether there were differences in the caregiver burden of the caregivers of patients with EOAD and LOAD.

Methods

Sample

A comparative descriptive study design was used in this study. The sample selection was performed using nonprobability convenience sampling. The study sample comprised 109 primary informal caregivers of community-dwelling patients with AD (34 EOAD and 75 LOAD). Those diagnosed with dementia before the age of 65 were included in the EOAD group, and those diagnosed after the age of 65 were included in the LOAD group. Patients were diagnosed with AD by a neurologist, who made the diagnosis based on clinical and cognitive assessments, laboratory test results, and neuroimaging findings. The National Institute on Aging-Alzheimer's Association criteria was used for probable AD.[21] The inclusion criteria for caregivers were as follows: they had to be a family member of the patients and the primary caregiver for at least 6 months. Caregivers with visual, hearing, or speech impairments were excluded. Moreover, for patients diagnosed with AD, the exclusion criteria were as follows: patients with psychiatric disorders such as severe depression, schizophrenia, and bipolar disorder, patients with other neurological diseases, and patients diagnosed with another type of dementia (vascular dementia, frontotemporal dementia, etc.) or comorbid AD (AD with vascular dementia).

Data collection

The study was conducted between June and December 2018 in the dementia outpatient clinic of one university hospital in the west of Turkey. Data were collected during routine controls of patients with AD at the outpatient clinic. The administration of the questionnaire took approximately 25 minutes. Approval to conduct the study was obtained from the ethical committee of the Dokuz Eylul University, Non-invasive Research Ethics Board (approval number: 2028/22-26, date: September 13, 2018). After the participants agreed to participate in the study (after written and oral permission had been obtained), they were instructed to complete the questionnaires.

Instruments

Several sociodemographic characteristic questionnaires, including the Caregiver Burden Inventory (CBI), the Mini-Mental State Examination (MMSE), the Neuropsychiatric Inventory (NPI), Barthel's Activities of Daily Living (Barthel's ADL), and the Clinical Dementia Rating (CDR) scale, were used. The CBI was used to examine the perceived caregiver burden for AD.[22] The CBI includes the following five domains of burden: time-dependence, developmental, physical, emotional, and social burden. Higher scores indicate a greater caregiver burden. Novak and Guest (1989) reported that Cronbach's α values of subscales range from 0.96 to 0.76. The validity and reliability of the CBI for the Turkish population were examined by Küçükgüçlü, Esen, and Yener (2009).[23] The Cronbach's α coefficient of the scale was 0.92. Moreover, Cronbach's α values of subscales ranged from 0.96 to 0.76. The MMSE was used to assess the cognitive function of patients with AD.[24,25] The NPI was used to assess neuropsychiatric symptoms.[26,27] Barthel's ADL were used to perform functional activities.[28,29] The CDR scale was used to determine the possible stages of cognition and function.[30] This study used the MMSE, NPI, Barthel's ADL, and CDR scores to control for variations in cognitive impairment, the functionality of patients with AD, and behavioral problems among care recipients of the caregivers of both the EOAD and LOAD groups.

Statistical analyses

All statistical analyses were performed using the SPSS version 22.0. Parametric variables were described by their means and standard deviations (SD). Independent t-test and chi-square test were used. The G-Power 3.1.9.7 statistical program was used for power analysis in this study. According to the post-hoc difference between two independent means analyses, a sample size of 75 for LOAD and 34 for EOAD, an effect size of 0.5, and an alpha value of 0.05 were considered, and the power of the study was found to be 0.78. In general, a power of 0.80 is appropriate for such studies. A p-value of <0.05 was considered significant.[31]

Results

Sociodemographic characteristics

Early-onset Alzheimer's disease group

The majority of patients in the EOAD group were women (61.8%, n=21). The mean age and educational level of the EOAD group were 61.26 (SD=4.93) years and 8.29 (SD=4.61), respectively.

The majority of caregivers were women (61.8%, n=21) and spouses (55.9%, n=19) of patients in the EOAD group. The mean age and educational level of caregivers were 50.32 (SD=13.03) years and 11.67 (SD=4.29) years, respectively.

Late-onset Alzheimer's disease group

The majority of patients in the LOAD group were women (56.0%, n=42). The mean age and educational level of the LOAD group were 80.10 (SD=5.39) years and 8.01 (SD=9.19) years, respectively.

The majority of caregivers were women (69.3%, n=52) and most children (61.3%, n=46) of patients in the LOAD group. The mean age and educational level of caregivers were 59.36 (SD=12.36) years and 10.94 (SD=4.14), respectively.

The ages of patients and caregivers in both groups were significantly different (p<0.001). Table 1 shows the sociodemographic characteristics of caregivers and patients in both groups.

Table 1. Characteristics of participants

Caregiver variables	**EOAD (34)** **n (%)**	**LOAD (75)** **n (%)**	**x^2**	**p**
Sex				
Female	21 (61.8)	52 (69.3)	0.606[a]	0.436
Male	13 (38.1)	23 (30.7)		
Income				
Income less than expenditure	5 (14.7)	19 (25.3)	1.545[a]	0.462
Income equal to expenditure	21 (61.8)	41 (54.7)		
Income more than expenditure	8 (23.5)	15 (20.0)		
Working status				
Working	12 (35.3)	20 (26.7)	0.840[a]	0.360
Not working	22 (64.7)	55 (73.3)		
Relationship with the patient				
Spouse	19 (55.9)	29 (38.7)	2.813[a]	0.093
Child	15 (44.1)	46 (61.3)		
	X±Ss	**X±Ss**	**t**	**p**
Age (years)	50.32±13.03	59.36±12.36	-3.476	0.001*
Education (years)	11.67±4.29	10.94±4.14	0.843	0.401
Caregiving period (years)	3.23±1.68	4.04±2.13	-1.939	0.055
Patient variables				
Age (years)	61.26±4.93	80.10±5.39	-17.346	0.000*
Education (years)	8.29±4.61	8.01±9.19	0.168	0.867
Diagnosis (years)	3.29±1.76	4.44±2.35	-2.530	0.013*
MMSE	16.76±6.00	15.44±7.09	0.945	0.347
NPI	24.02±20.91	32.08±22.07	-1.792	0.076
Barthel ADL	81.32±21.29	73.20±24.55	1.665	0.099
	n (%)	**n (%)**		
Sex				
Female	21 (61.8)	42 (56.0)	0.319[a]	0.572
Male	13 (38.2)	33 (44.0)		
CDR				
1 (Mild)	20 (58.8)	35 (46.7)	2.175[a]	0.337
2 (Moderate)	11 (32.4)	26 (34.7)		
3 (Severe)	3 (8.8)	14 (18.7)		

a:Yates corrected chi-square test, X:Mean, SD:Standard deviation, t:Independent t-test, MMSE: Mini mental state examination, NPI: Neuropsychiatric inventory, CDR: Clinical dementia rating scale, ADL: Activity of daily living

Results of caregiver burden

Factors affecting caregiver burden, including sex (p=0.436), income (p=0.462), working status (p=0.360), relationship with patients with AD (p=0.093), educational level (p=0.401) and caregiving period (p=0.055), were similar for both EOAD and LOAD. Factors of patients with AD affecting the burden, including MMSE scores (p =0.347), NPI scores (p=0.076), Barthel's ADL scores (p=0.099) and CDR scale scores, (p=0.337) were similar for both EOAD and LOAD.

The caregivers of the EOAD group had more social burden than the caregivers of the LOAD group (p=0.002). Moreover, the caregivers in the EOAD group had a greater developmental, physical, and total burden than the caregivers of the LOAD group. A comparison of the mean scores on the caregiver burden and subscales is shown in Table 2.

Table 2. Comparison of the mean scores on the caregiver burden inventory and its subscales

	EOAD (34)	LOAD (75)		
Caregiver burden and subscales	**X±Ss**	**X±Ss**	**t**	**p**
Time-dependence burden	8.32±6.25	10.00±6.63	-1.244	0.216
Developmental burden	8.05±3.89	6.37±4.95	1.752	0.083
Physical burden	6.98±4.54	5.55±5.38	1.343	0.182
Emotional burden	2.17±3.23	2.17±3.39	0.005	0.996
Social burden	5.64±3.65	3.26±3.64	3.156	0.002
Caregiver burden	31.19±11.52	27.37±15.26	1.443	0.153

X:Mean, SD:Standard deviation, t: Independent t-test

Discussion

The caregivers in the EOAD group reported a higher caregiver burden than the caregivers in the LOAD group, but the difference between the two groups was not statistically significant. The higher level of caregiver burden among the caregivers in the EOAD group was consistent with the findings of other studies.[4,17,20] The caregivers of patients with EOAD are less prepared to play the role of caregiver than the caregivers of patients with LOAD.[32] The closeness inherent in the spousal relationship and the loss of identity that occurs when considering the caregiver's role rather than the normative spousal's role undoubtedly changes the perception of the caregiver.[9] In addition, people with EOAD may still be working, but the symptoms of dementia may lead to loss of employment.[33] This situation also impacts workforce participation and finances for caregivers.[34] In this study, the caregivers of EOAD experienced more burden than the caregivers of LOAD may be due to their lower readiness to care. Furthermore, the study did not question the status of patients with AD to continue work or leave the job. This situation may have affected the caregiver's burden. Different from most previous studies, in this study, the caregiver burden was examined in terms of time-dependency, developmental, physical, social, and emotional burden according to the onset of the disease.

Time-dependence burden

The time-dependence burden, which defines the burden caused by the limited time of caregivers, showed a tendency towards being higher in the caregivers of the LOAD group, but this was not statistically significant. Children who care for their parents with AD might be more inclined to appeal for care services and often spend less time providing care.[18,35] In our study, 61.3% of caregivers of patients with LOAD were their children. Elderly individuals often care for patients alone; thus, they spend more time on care. With aging, the incidence of chronic diseases increases, and additional diseases are observed besides AD. Caregiving can include everything from assisting with ADL and providing direct care to navigating complex health care.[36] Caregivers are thought to bear a greater time-dependence burden because people with LOAD are mostly in the moderate and severe stages and have lower Barthel's ADL scores. Another reason may be that elderly caregivers have more difficulty with physically demanding activities than younger caregivers.

Developmental burden

The developmental burden, which defines the burden caused by the feeling that caregivers are not where they should be with their peers in their lives, was higher in the caregivers of patients with EOAD than in the caregivers of patients with LOAD, but this difference was not statistically significant. AD is rare in younger people. The caregivers of patients with EOAD are also more directly affected in their daily lives as it concerns the spousal relationship.[18] Younger caregivers may be experiencing more developmental burden because they are not prepared for a caregiver role and are not similar to their peers.

Physical burden

The physical burden, which defines the feelings of chronic fatigue and physical health of the caregiver, was higher in the caregivers of patients with EOAD than in the caregivers of patients with LOAD, but this difference was not statistically significant. Numerous studies show that caregiving responsibilities can be challenging, and the caregivers of patients with EOAD often have high levels of physical complaints.[4,9,13,18,37] In our study, it was an expected result that the caregivers of patients with EOAD would experience more physical burden than the caregivers of patients with LOAD. Caregivers of EOAD are thought to have more physical symptoms because they are more psychologically affected during the caregiving process.

Emotional burden

The emotional burden, which defines the negative emotions of caregivers toward the patient they care for, was similar in both caregiver groups. During the caregiving process, caregivers experience many negative emotions like anger, embarrassment, frustration, grief or guilt, loneliness, and poor emotional well-being.[4,38] The caregivers of patients with EOAD experienced mild-to-severe depression and had mild-to-moderate depression scores.[11] Similarly, the caregivers of patients with EOAD experience emotional burdens.[39] Caregiving is a process that affects family dynamics and relationships. This can be explained by the fact that the caregivers of patients with AD experience a similar emotional burden because the caregiving process affects their relationships with family members.

Social burden

The social burden, which defines problems related to caregiver roles in work or family life, was higher in caregivers of EOAD patients than in caregivers of LOAD patients. The caregivers of patients with EOAD are less likely to be prepared for their role as the primary caregiver and are still in a more active work and social life phase than the caregivers of patients with LOAD. Ducharme et al. (2016) stated that the caregivers of patients with EOAD may be more socialized to use services and help from outside informal support networks (family, friends, and neighbors) than the caregivers of patients with LOAD.[9] However, several younger caregivers experience a sense of stigma and feel uncomfortable sharing the diagnosis with others.[18,40] The increasing and time-consuming care demands affect their ability to perform professional work. They also feel limited in their social activities.[18] For these reasons, they might feel more socially burdened than others. In the data collection process, data on the intensity and type of caregiving activities performed by caregivers within the caregiving period were not collected.

Limitations and Strengths of Study

The strength of the current study is that, to the best of our knowledge, comparing different dimensions of caregiver burden according to the age of onset of AD is limited in the literature. Hence, our study adds important findings regarding the different dimensions of caregiver burden based on the age of onset of AD.

Clinically, our findings provide data that highlight the differences that should be considered when offering services tailored to the needs of caregivers of patients with AD. These comparative results can be used to develop targeted professional support interventions for AD family caregivers.

Several limitations have to be considered in our study. First, in the data collection process, data on the intensity and type of caregiving activities performed by caregivers within the caregiving period were not collected. Second, the emotional aspects of caregivers, such as depression and anxiety, were not evaluated. The sample size was relatively small, and the power of the study was in a limited range. This should be kept in mind when interpreting the study's findings. Future studies should be conducted with a larger sample size and greater power.

Conclusions

AD, which is the most common cause of dementia, has been a health concern due to its serious consequences for patients, their caregivers, and healthcare services. To adequately support caregivers, it is important to determine whether the onset of AD affects the caregiver burden. Our study adds valuable information to the scarce literature on the comparison of caregiver burden between EOAD and LOAD caregivers. The results of this study suggest that the caregivers in the EOAD group had a significantly higher social burden score than the LOAD group. In addition, caregivers of EOAD tended to have higher caregiver burdens across many types of subjective burdens, but this was not statistically significant. Further research should be conducted to better understand the differences in family caregiver burden of AD based on the age of onset of AD. The effect of caregivers' readiness to care for individuals with EOAD and LOAD on caregiver burden can be investigated in future studies.

Implications for Practice

This comparative study highlighted the similarities and differences in caregiver burden based on the age of onset of AD. A novel finding was that the caregivers of patients with EOAD had a higher social burden than the caregivers of patients with LOAD. Caregivers of patients with EOAD should be evaluated and supported in terms of their social burden.

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