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Effects of Social Support Levels and Caregiver Burden on Quality of Life of Caregivers of Patients with Alzheimer's Disease

Alzheimerlı Hastalara Bakım Verenlerin Sosyal Destek Düzeylerinin ve Bakım Yüklerinin Yaşam Kalitesine Etkisi

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Öz

Giriş ve Amaç: Alzheimerlı hastalara bakım verme fiziksel ve psikiyatrik açıdan önemli negatif sonuçlara sahip olduğu için alzheimerlı hastalara bakım verenlerin yaşam kalitesi üzerine artan bir vurgu vardır. Bu çalışmanın amacı, alzheimerlı hastalara bakım verenlerin sosyal destek düzeyleri ve bakım yüklerinin yaşam kalitesinin her bir alanında sahip olduğu etkiyi açıklamaktadır.

Gereç ve Yöntemler: Bu çalışmada basit bir rasgele kolaylık örnekleme tasarımı kullanılmıştır.

Bulgular: Bakım verenlerin büyük çoğunluğu kadın (71.5%), ortalama yaş 41.8±11.5 idi. Bakım verenlerin ortalama sosyal destek skoru 1.80±1.03 idi. Tek değişkenli çözümlemede sosyal destek yaşam kalitesini olumlu yönde etkiledi. Tek değişkenli çözümlemede işlevsel olmasına rağmen sosyal destek çok değişkenli çözümlemede yaşam kalitesine etkisini yitirdi. Tek değişkenli çözümlemede olduğu gibi çok değişkenli çözümlemede de bakım yükü yükseldikçe bakım verenlerin yaşam kalitesi düşmekteydi ($p<0.001$). Bakım yükünde her bir birimlik artışa karşılık yaşam kalitesinin tüm alanlarında 7-9% oranında bir kötüleşme söz konusu idi.

Sonuç: Bakım verme ve yaşam kalitesi ilişkisi birbiri ile uyumlu gözükmektedir. Bu nedenle bakım alanın hastalığının zorluk derecesine bağlı olarak bakım verenin bakım yükünün artması ile yaşam kalitesi etkilenir. Bu fikir, bakım yükünde her bir birimlik artışın yaşam kalitesinde düşmeye neden olduğunu gösteren sonuçlarımızla tutarlıdır. Çalışma bulguları, alzheimerlı hastalara bakım verenlerin yaşam kalitesi ile bazı psikososyal özellikleri arasındaki ilişkileri değerlendirirken öncelikle bakım yükünü azaltmaya yönelik müdahalelere odaklanmak gerektiğinin ve bakım yükünün yaşam kalitesinin tüm boyutlarında göz ardı edilmemesinin önemini gösterdi.

Anahtar Kelimeler: Alzheimerlı hastalar, Bakım verenler, Bakım yükü, Sosyal destek, Yaşam kalitesi.

Abstract

Objective: There is an increasing emphasis on the quality of life of caregivers of Alzheimer's patients since caregive for Alzheimer's patients has significant negative consequences from physical and psychiatric aspects. The purpose of this study was to explain the effects of social support and caregiving burden on each domain of the quality of life (QOL) of caregivers of patients with Alzheimer's disease.

Materials and Methods: This study employed a simple random convenience sampling design.

Results: The vast majority of caregivers were female (71.5%), and their average age was 41.8±11.5 years. Caregivers' mean social support score was 1.80±1.03. In the univariate analysis, social support positively affected quality of life. However, this effect was not observed in the multivariate analysis. In both the univariate and multivariate analyses, caregivers' quality of life decreased with an increase in caregiving burden ($p<0.001$). There was a worsening of 7-9% in all domains of quality of life in response to each unit increase in caregiving burden.

Conclusion: Caregiving and QOL are associated; QOL is affected by the increase in caregiving burden depending on the severity of the disease of the person receiving care. This idea is consistent with the results of the present study showing that each unit increase in caregiving burden causes a decrease in QOL. The findings of this study emphasize the necessity of accounting for caregiving burden in all dimensions of quality of life while evaluating the relationships between quality of life and some psychosocial characteristics of caregivers of patients with Alzheimer’s disease.

Keywords: Alzheimer’s, Caregivers, Caregiving burden, Quality of life, Social support.

1. Introduction

Alzheimer’s disease (AD) is a chronic neurodegenerative disease characterized by the progressive loss of cognitive and functional skills [1]. The global prevalence and incidence of AD are rapidly increasing, and according to the World Alzheimer Report, in 2016, more than 47 million people were living with the disease. This number is projected to exceed 131 million by 2050 [2]. AD is usually observed around the age of 65. While the incidence of the disease is 10.3% at the age of 65 and above, it reaches 30-47% at the age of 85 and above [3-4]. Among 5.5 million people only in the USA, one in every 10 people aged 65 and above has AD [5]. In Turkey, there are 6651503 people aged 65 and above, and 4.3% of all annual deaths (11.997 deaths) are due to AD [6]. While these figures show an increasing threat from and interest in the disease, the global prevalence of undiagnosed AD is estimated to be fairly high. Even when the diagnosis is made, the care provided is often unsatisfactory for both the patients and their caregivers [2]. Therefore, AD places heavy psychosocial and lifestyle-related responsibilities on caregivers.

The difficulty in fulfilling the expected roles within the family, limitation in social activities, and increase in dependence that accompany the progression of the disease lead to a high incidence of depression and anxiety [7] and in caregivers’ social support requirements [8-9]. Social support is associated with, on the one hand, psychological distress, depression, and stress, and on the other, self-esteem, adaptation, and positive feelings. Increased social support in caregivers is correlated with improved self-esteem, adaptation, health, and prosocial behaviors and decreased depression, stress, and unhealthy psychological symptoms [10].

The positive effects of social support on physical and psychological health have been reported [11-13]. Social support acts as a buffer against stress [11], and individuals who receive social support are healthier than those who do not [12]. There are positive relationships between the adequate use of social support mechanisms by caregivers of patients with chronic diseases and the reduction rate of attacks patients experience [13]. Family and friends form caregivers’ most important social support resource. It is known that social support from these sources is positively related to positive feelings and subjective well-being and negatively related to emotional distress [14]. Furthermore, caregivers can receive social support from other caregivers they meet during the disease process, as well as non-governmental organizations. The cognitive evaluation of the presence and adequacy of externally provided social support [15] can decrease caregivers’ burden and positively affect their quality of life (QOL).

AD poses a significant challenge for both patients and caregivers. Caregivers of patients with AD experience significant negative consequences owing to the physical and psychiatric aspects of providing care [16]. The caregiver is someone the patient is dependent on and who helps the patient meet his/her physical, emotional, and social needs [17]. Previous studies have shown that the process of providing care restricts caregivers’ freedom and domestic lives, perhaps even causing them to lose their jobs and leading to the deterioration of their social relationships [18-19]. However, while caregiving may cause difficulties, it also has positive aspects: it can facilitate the development of close relationships, increase love, make the meaning of life clearer through the experience gained, lead to personal development, increase social support, help achieve personal satisfaction, and strengthen self-respect [20-21].

However, caregiving for a family member with AD is a particularly stressful situation because of the patient’s unpredictable and unbalanced moods and behaviors. In such a situation, caregivers have been known to report broken family ties and high levels of difficulty in providing the best possible care [21]. A study showed that caregivers of patients with AD had significantly more stress and illnesses compared to caregivers of patients with other chronic diseases [22]. Other studies have emphasized that the disease has an effect on the lives of caregivers and requires long-term care; in addition, the caregiver’s advanced age, closeness to the patient, coping skills and beliefs, voluntary nature of caregiving, and support received in the caregiving process shape the caregiving burden [23-26].

The complexity of the process and the number of difficulties they experience clearly contribute to the burden of caregivers of patients with AD [27]. Burden is defined as ‘negative objective and subjective consequences’ such as social, economic, and physical health problems resulting from the provision of care, deterioration of family relations, psychological distress, and feelings of loss of control [28].

Moreover, caregivers who use emotion-oriented or avoidance coping strategies experience extra burden [29]. Caregivers have to find practical solutions to many problems apart from their own sadness and the duties for which they are responsible, leading them to engage in existential questioning. Therefore, the accurate determination of caregiving burden and the fulfillment of caregivers' needs will improve their QOL.

In conclusion, caregiving burden can be considered an emotional response to care requests. Caregiving burden and social support are two among many indicators of QOL [30]. QOL is difficult to measure because it is not easy to gauge how an individual perceives his/her own physical, psychological, social, and existential functioning. A broad concept that covers all domains of life and that is influenced by various factors, QOL has become a distinctive issue in the treatment of chronic diseases [31-33]. Nevertheless, there is limited information on how the QOL of caregivers of patients with AD changes over time [34]. AD is a non-infectious disease that affects, and is affected by, various factors. The caregiving process, which is potentially changeable, may have positive effects on QOL. For this reason, social support and caregiving burden may play a significant role in the QOL of caregivers of patients with AD.

Study aims

There is an increasing emphasis on the QOL of caregivers of patients with AD. Numerous studies [1, 22, 27, 30-31, 34-38] provide insight into QOL by focusing on concepts such as depression, stress, anxiety, coping, and spirituality in caregivers of patients with AD, the difficulties experienced in the caregiving process, and the effects of caregiving on the health of caregivers and family functioning. Furthermore, the number of studies that focus on the variables of caregiving burden and QOL in caregivers of patients with AD is also increasing [16, 24, 39-45]. However, as far as we know, there is no Turkish study that focuses on the effects of social support levels and caregiving burden on the QOL of caregivers of patients with AD. Therefore, the objective of this study was to explain the effects of social support levels and caregiving burdens on each QOL domain of caregivers of patients with AD.

The specific aims were:

1.To describe the sociodemographic characteristics of caregivers of patients with AD.

2.To describe the relationships of QOL domains with social support levels and caregiving burden.

3.To explain the factors that predict caregivers' QOL.

2. Materials and Methods

2.1.Participants

In the study, the general screening technique of the quantitative research method was used, and the relational screening approach was adopted. However, this study also had a descriptive aspect. Simple random sampling was adopted. First, the list of registered caregivers was obtained from the Istanbul and Izmir branches of the Turkish Alzheimer Association. The study was completed with 200 caregivers who were selected from these two lists.

The vast majority of participants were female (71.5%). A significant proportion of the participants belonged to nuclear families (65.2%), and 63% of them were married. Of the remaining participants, 12% were divorced, 14% were single, and the spouses of 11% were deceased. The ratios of those who belonged to extended and single-parent families were 26.8% and 8.1%, respectively. Among the participants, 75.5% had an educational level of high school and above. Caregivers' ages ranged from 20 to 74, and the average age was 41.8±11.5 years. The average monthly income was 2294±1366 ₺ . Of all the caregivers, 51% reported having health problems (any disease, disability, or need for psychological support), and 27% of this group reported having a chronic disease. Furthermore, 34.5% of the participants stated that they received psychological support during the caregiving process. Caregivers received the highest support from their families (68%), friends (29.5%), other caregivers (27%), and non-governmental organizations (25.5%). Few (10%) stated that they received support from their neighbors. Caregivers' social support scores ranged from 0 to 5, and the mean social support score was 1.80±1.03.

2.2.Procedures

Data were collected through questionnaires administered to caregivers of patients with AD who understood the purpose of the study and provided informed consent. The average completion time was 15 minutes. Ethical approval was obtained from the Hacettepe University Ethics Commission followed by the Istanbul and Izmir branches of the Turkish Alzheimer Association. Before final data collection, a pilot application of the questionnaire was performed with participants (n=15) who were randomly selected from among the caregivers registered to the Istanbul branch of the Turkish Alzheimer Association. All data collected were based on personal interview reports.

2.3.Instruments

Sociodemographic Information Form. In light of the feedback received from caregivers as part of the pilot study, the researchers revised the sociodemographic information form. The final form consists of nine basic questions (age, gender, monthly income, presence of any chronic disease or disability). Attention was paid to ensuring that the questions were unbiased and clearly stated.

2.4.Social Support

Five dimensions of social support—from family, friends, relatives, neighbors, and non-governmental organizations—were individually examined. The presence of support received from each person or group was encoded as 1, and the absence of it was encoded as 0. The sum of the answers to these questions constitutes the social support score. In the distribution of scores ranging from 0 to 6, higher scores indicate the presence of social support from an increasing number of dimensions.

2.5.Caregiver Burden Inventory

The Caregiver Burden Inventory is a 24-item scale developed by Novak and Guest [75], which takes a multidimensional view to caregivers' burden. Its suitability for the Turkish context was tested by Küçükgüçlü et al. [28]. Turkish translation, back translation, and preliminary application of the scale were performed to ensure its language equivalence/adaptation. A strong linear correlation was determined as a result of the test-retest that was performed to test the time invariance of the inventory (r=0.98). Cronbach's alpha was determined to test internal consistency; the value for the entire scale was 0.94, 0.93 for time-dependence, 0.94 for developmental burden, 0.94 for physical burden, 0.82 for social burden, and 0.94 for emotional burden [28].

2.6.World Health Organization Quality of Life Scale-Short Form (Turkish version).

The World Health Organization Quality of Life Scale-Short Form (WHOQOL-BREF), the Turkish validity and reliability of which was determined by Eser et al. [46], includes 26 questions across four sub-domains—physical, psychological, social, and environmental—and has no separate sections. Since each QOL domain is important in itself, it shows the changes in these domains and evaluates the caregiver in his/her environment. The highest internal consistency values (Cronbach's alphas) of the WHOQOL-BREF (TR) were found in the physical domain (0.83 and 0.79) and the lowest value was found in the social domain (0.53) in both diseased and healthy individuals [46].

2.7.Statistical Analyses

The findings were first examined in terms of descriptive characteristics. While number and percentage distributions were presented for the values obtained by census, mean±standard deviation and the minimum and maximum values were emphasized in the measured variables. Ordinal logistic regression analysis was applied in the univariate and multivariate analysis of the main factors that determine caregivers' QOL, and the results were reported in the form of odds ratio (OR) and 95% confidence interval (CI). The variables that were significant in the univariate analysis were tested in the multivariate analysis. The caregive burden inventory scale total score (sub-dimensions were not included) was included in the multivariate analysis. SPSS 21.0 and Stata 14.0 were used for analysis.

3. Results and Discussion

3.1. Results

The results of the univariate analysis of the relationship of caregivers' QOL with their social support levels and caregiving burden are presented in Table 1.

Table 1. Relationships between caregivers' social support level, caregiving burden, and quality of life (univariate ordinal logistic regression analysis).

	PHYSICAL	**PSYCHOLOGICAL**	**SOCIAL**	**ENVIRONMENTAL**
	OR (95% CI)	**OR (95% CI)**	**OR (95% CI)**	**OR (95% CI)**
Gender (female)	1.00 (0.59-1.72)	1.43 (0.83-2.46)	1.39 (0.82-2.37)	1.51 (0.88-2.58)
Age	**0.95 (0.94-0.98)*****	**0.98 (0.96-0.99)***	0.98 (0.96-1.00)	0.99 (0.98-1.02)
Family type (extended + fragmented)	1.03 (0.62-1.70)	1.01 (0.61-1.69)	1.51 (0.90-2.52)	1.16 (0.70-1.91)
Educational status (high school and above)	**2.60 (1.47-4.59)****	**2.13 (1.22-3.74)****	1.26 (0.72-2.21)	1.41 (0.79-2.53)
Monthly income (₺) (2301 and above)	**4.86 (2.84-8.31)*****	**5.34 (3.11-9.17)*****	**2.07 (1.25-3.43)****	**2.31 (1.39-3.81)*****
Marital status (Married)	1.16 (0.7-1.91)	0.77 (0.47-1.28)	0.8 (0.48-1.33)	0.85 (0.51-1.42)
Presence of health problems	**0.19 (0.11-0.33)*****	**0.20 (0.12-0.34)*****	**0.32 (0.19-0.52)*****	**0.33 (0.20-0.54)*****
Social support score	**2.21 (1.71-2.88)*****	**1.97 (1.54-2.52)*****	**1.85 (1.45-2.37)*****	**1.69 (1.33-2.15)*****
Time dependence	**0.84 (0.79-0.88)*****	**0.83 (0.79-0.88) *****	**0.83 (0.79-0.88)*****	**0.80 (0.76-0.85)*****
Developmental burden	**0.75 (0.71-0.80)*****	**0.71 (0.67-0.76)*****	**0.73 (0.69-0.78)*****	**0.70 (0.66-0.75)*****
Physical burden	**0.76 (0.72-0.81)*****	**0.73 (0.69-0.78)*****	**0.79 (0.75-0.83)*****	**0.77 (0.73-0.81)*****
Social burden	**0.76 (0.72-0.81)*****	**0.70 (0.66-0.75)*****	**0.74 (0.70-0.78)*****	**0.74 (0.70-0.79)*****
Emotional burden	**0.80 (0.76-0.85)*****	**0.73 (0.69-0.77)*****	**0.83 (0.79-0.87)*****	**0.81 (0.77-0.85)*****
Total caregiving burden score	**0.92 (0.91-0.94)*****	**0.91 (0.90-0.93)*****	**0.93 (0.92-0.94)*****	**0.92 (0.91-0.93)*****

* $p<0.05$, ** $p<0.01$, *** $p<0.001$
OR (95% CI): Odds Ratio (95% Confidence Interval)

High school education and above positively affected the physical and psychological domains of QOL, and high income and social support levels positively affected all domains. Contrarily, increasing age negatively affected the physical and psychological domains of QOL. Moreover, in the examination of the relationship between caregiving burden and QOL, all domains were negatively affected by increasing caregiving burden (p<0.05). In particular, there was a significant negative relationship between all sub-dimensions and the sum of the caregiving burden and all domains of QOL. Each unit increase of total caregiving burden led to an 8% decrease in the physical domain of QOL, a decrease of 9% in the psychological domain, a decrease of 7% in the social domain, and a decrease of 8% in the environmental domain (p<0.001). The multivariate ordinal logistic regression model adjusted according to age and gender by taking into account the significant results obtained from the univariate analyses for each QOL domain is depicted in Table 2.

Table 2. Factors predicting caregivers' quality of life (multivariate ordinal logistic regression analysis).

	PHYSICAL	**PSYCHOLOGICAL**	**SOCIAL**	**ENVIRONMENTAL**
	OR (95% CI)	**OR 95% CI)**	**OR (95% CI)**	**OR (95% CI)**
Educational status (high school and above)	0.87 (0.43-1.78)	0.94 (0.45-1.95)	NI	NI
Monthly income (₺) (2301-8000)	**5.70 (3.05-0.65)***	**8.74 (4.49-17.05)***	**1.85 (1.08-3.16)***	**2.07 (1.21-3.56)****
Presence of health problems	**0.44 (0.24-0.81)***	**0.31 (0.18-0.58)***	0.73 (0.41-1.31)	0.82 (0.45-1.49)
Social support score	1.16 (0.86-1.54)	1.08 (0.81-1.45)	1.14 (0.86-1.51)	0.88 (0.66-1.17)
Total caregiving burden	**0.93 (0.92-0.95)***	**0.91 (0.89-0.93)***	**0.93(0.92-0.95)***	**0.91 (0.89-0.92)***

OR (95% CI): Odds Ratio (95% Confidence Interval)
* p<0.05, ** p<0.01, *** p<0.001
Each analysis model was adjusted according to age and gender.
NI: Not included in the model.

According to the multivariate ordinal logistic regression analysis, while having health problems negatively affected the physical (OR=0.44; 95% CI 0.24-0.81) and psychological (OR=0.31; 95% GA 0.18-0.58) domains of QOL, higher income had a positive effect on all domains (OR=5.70; 95% CI 3.05-10.65, OR=8.74; 95% CI 4.49-17.05, OR=1.85; 95% CI 1.08-3.16, OR=2.07; 95% CI 1.21-3.56). The significant relationship between high social support score and QOL obtained in the univariate analysis was not found in the multivariate model. However, each unit increase in the total caregiving burden score had a negative effect on all QOL domains (p<0.001). In brief, caregivers' QOL decreases as caregiving burden increases. This decrease is at the level of 7% (physical and social domains) and 9% (psychological and environmental domain) in all domains of QOL in response to each unit increase in caregiving burden.

3.2. Discussion

Using simple random sampling, this study attempted to determine the effects of social support and caregiving burden of caregivers of 200 patients with AD on their QOL. Although our results were generally consistent with those of previous studies, there were some variations. The vast majority of caregivers had an educational level of high school and above, were female, were at the beginning of middle adulthood, and had a lower-middle economic income level and low social support as per Turkish standards. An educational level of high school and above among caregivers of patients with AD made a positive contribution to their QOL both in the current study and previous ones [44, 47-48]. In previous studies conducted to determine the expectations and difficulties of caregivers in Turkey [49-50], the majority of caregivers were female, were at the beginning of middle adulthood, had a lower-middle economic level, had difficulties owing to caregiving, and did not receive support in the caregiving process.

In other studies, carried out with relatives who were primary caregivers of patients with AD, the majority of the participants were female [35, 51]. Studies emphasize that social traditions and gender patterns thrust the 'caregiver' role upon women, which is consistent with the present study [36, 52-53]. In collectivist cultures like Turkey, caring for relatives is traditionally expected, and individuals perceive it as their duty and responsibility. Every society differentiates between 'male' and 'female' roles; in Turkey, women's 'caregiver' role comes to the fore [49]. It is difficult to provide round-the-clock care to an ill family member [54], and the situation is further complicated when the entire burden of caregiving is imposed on a single person, most often women. However, in Turkey, women may not object to this situation because they consider caregiving an extension of their responsibilities, whereas men are strangers to the caregiving process [55]. No effect of gender on caregiving burden was observed in the univariate model in the present study; however, in a study that attempted to reflect the effects of caregivers' gender on their burden [56], females' average scores on the caregivers' burden inventory and all its sub-dimensions were found to be statistically significantly higher compared to male caregivers. Another study emphasized that the developmental burden mainly affected women, and that time-dependent burden was associated with caregivers of advanced aged [41]. Moreover, physical and emotional burdens were more severe both in female caregivers and those of advanced age. Another study indicated that low income, increasing age, and caregiving burden were associated with poor QOL [57]. These results are at least consistent with the findings of the present study, in which we demonstrated that increasing age affected caregivers' QOL.

However, some studies placed particular importance on social support [14, 58-63]. A previous study stated that the lack of social support was among the factors shaping the stressors of caregivers [58]. Another study showed that social support was one of four variables affecting caregivers' QOL (patient and caregiver characteristics, coping, stress, social support) [61]. Although there are studies emphasizing that social support is linearly associated with QOL [14, 59], in one study, social support was one of the important variables that statistically predicted caregivers' stressors [58]. In another study, social support also had an effect in the reduction of depression levels of caregivers of patients with AD and played a mediating role in reducing caregiving burden and increasing QOL [62]. In one study, it was emphasized that the use of family and friend relationships from social support networks should be brought to the forefront to help the caregivers of patients with AD [63]. Finally, in a different study, caregivers' disease management levels were found to be lower in cases where there was no general or disease-specific social support [60]. This idea was supported by another study that reached the conclusion that caregivers must receive economic, social, and psychological support [64]. The findings of the present study also showed that family type and marital status, apart from gender, in the univariate model, and educational status and social support (social support was functional in the univariate analysis) in the multivariate model, lost their effects on QOL. Although studies have achieved different results [14, 56, 59, 61, 63] the variations could be attributable to our sample and methodology. We cannot surely say that this result does not have a direct effect on QOL since social support refers to the perception of assistance received from the social environment; however, it seems unlikely because of its positive role in the decrease of caregiving burden and its indirect association with QOL. Indeed, in a study [38], the factors improving caregivers' QOL were caregivers' independence, low caregiving burden, and care support. Care support may be correlated with the social support provided by the environment. Our opinion about the correlation between care support and social support was also approved by other studies that found significant relationships between caregiving burden and social support and that directly observed that social support modification reduced caregiving burden [30, 65-66].

One of the most important findings of the present study was the depiction of a decrease of 7-9% in all domains of QOL in response to each unit increase in participants' caregiving burden. This result is important in that it demonstrates that social support, which was effective in univariate analyses, was not as functional as caregiving burden in the multivariate model. In studies describing the relationship between caregiving burden and QOL of caregivers of patients with AD, caregiving burden had significant effects on QOL [48, 67]. In a study comparing the general population and caregivers, caregivers' average QOL score was lower than that of the general population [68]. Similar to the present study, others have shown that increasing caregiving burden has a significant effect on the decrease in caregivers' QOL [39, 42-43]. In previous studies [69-70], it was understood that there were two ways to achieve success in the treatment of AD. The first one was cognitive symptom-focused treatment, and the second was treatment aimed at eliminating the findings occurring during the course of the disease, and improving caregivers' QOL and increasing the support they receive. As the ultimate goal was to resolve caregivers' problems by improving their QOL, it was encouraging to see that caregiving burden in the caregivers of patients with AD affected their QOL. Furthermore, when the QOL was brought to agenda, the biopsychosocial approach to treatment seemed most appropriate because of health system deficits; in other words, professional psychosocial intervention methods are not commonly used in our country, and caregivers must be treated for their burden while patients undergo treatment for the disease.

Caregivers who have unmet needs or high levels of burden have a low QOL and experience difficulties in providing effective care [40]. In parallel with the results of the present study, Zaybak et al. [71] stated that caregivers' health perception had an effect on caregiving burden. In a study reviewing the scientific research in the literature on AD, it was concluded that the caregivers of patients with AD coped with intense physical and mental health problems [72]. There were also studies suggesting different evidence-based intervention methods to decrease the burden of caregivers of patients with AD and to improve their QOL [73]. It was remarkable that it was indicated in a study that caregiving for a family member with AD might lead to the feeling of living with a burden that could decrease the caregiver's QOL [74].

4. Conclusion

4.1.Research Limitations

This study had some limitations. The first was mediator variables that were not discussed in detail but that can have an effect on QOL (patient and caregiver characteristics, despair, depression, family functionality, stress, anxiety, coping, disease management). The second limitation was related to the self-reporting of all data collected and the evaluation of them within themselves. Caregivers were the relatives of patients with AD in a certain age group. Different results can be obtained when studies are carried out for specific caregivers of patients with AD (e.g., spouses) in a slightly different age group compared to the present study. The third limitation was the exclusively Turkish sample. Future studies should consider samples from other countries to facilitate comparisons. The last limitation is that the findings are not generalizable and must be interpreted with caution. The first reason for this is the simple random sampling design; based on the determination of the sample group, it only allowed for the choosing of participants according to the chance factor. Such a design is suitable only for small-scale studies, although all members of the population were equally likely to be selected. The second reason is the study's limited ability to represent the general population because of the restriction of participants to members of an association. An attempt to partially eliminate this limitation was made by performing the data collection process in two metropolises where 22% of Turkey's population lives. However, the variables affecting the QOL of caregivers of patients with AD should be studied in larger-scale studies that adopt different sampling methods (e.g., in populations where the entire all participants' list is difficult to find).

4.2.Implications for Practice

Caregiving and QOL are associated; QOL is affected by the increase in caregiving burden depending on the severity of the disease of the person receiving care. This idea is consistent with the results of the present study showing that each unit increase in caregiving burden causes a decrease in QOL. When the findings are taken into account, caregiving burden, which is affected by social support levels, is an important indicator of QOL. Caregiving burden must, therefore, form the focus of efforts to improve the QOL of caregivers of patients with AD.

As AD is still not fully understood, adequate preventive treatment is lacking. Treatment should be aimed at comorbid psychiatric disorders during the course of the disease, the training of the patient and caregiver, and the preservation and improvement of QOL. Indeed, psychosocial support services are needed to improve the QOL of caregivers of patients with AD. Disease management and AD caregiving training programs specific to caregivers with high psychosocial components can decrease their burden in the fight against AD and help improve their QOL. It is a good idea to meet the educational and informational needs of caregivers of patients with chronic illnesses. In conclusion, the present study showed that it is important to focus on interventions to decrease caregiving burden, and that caregiving burden in all dimensions of QOL should be considered while evaluating the relationships between QOL and some psychosocial characteristics of caregivers of patients with AD.

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[2] Turkish Lira (₺), national monetary unit. As of February 19, 2020, 1 Euro=6.56 TL and 1 Dollar= 6.08 TL, with a fixed daily exchange difference.

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