■ Original Article

# The burden of care on caregiver family members of elders and related factors in Izmir

*İzmir'de yaşlılara bakım veren aile üyelerinin bakım verme yükü ve ilişki faktörler*

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## ABSTRACT

**Aim:** We aim at investigating the burden of care and additional related factors of individuals over 65 years old and their caregiving family members who receive home care services from Bornova District Municipality of Izmir Province.

**Material and Methods:** The study was designed as a cross-sectional study. The sociodemographic characteristics of the caregiving family member, the data forms about the care information, and the Zarit caregiving burden scale were used to measure the burden of care status. Questionnaires addressing Sociodemographic characteristics, daily living activities and instrumental daily living activities were applied to elderly individuals. Data were analyzed using Student-t-test, Mann-Whitney U analysis, Analysis of Variance (ANOVA), Kruskal-Wallis variance analysis, and linear regression analysis; $p < 0.05$ was considered significant.

**Results:** The average burden of care on caregivers was $31.95 \pm 13.33$. Most of the caregivers were female, married, having low education, social security, having children, housewives. According to the results of linear regression analysis, a statistically significant relationship was found between the caregiving family member's health perception, sleep quality status, presence of physical and economic problems, daily and instrumental life activity status of the elderly and caregiving burden of the caregiving family member.

**Conclusion:** Providing support services for the physical and economic problems of caregivers and interventions to make elderly individuals independent may significantly reduce the care burden of caregiving family members.

**Keywords:** Caregiver burden; caregivers; elderly; family caregivers; home care

## ÖZ

**Amaç:** İzmir İli Bornova İlçe Belediyesi'nden evde bakım hizmeti alan 65 yaş ve üzeri bireylere bakım veren aile bireylerinin bakım yükü ve ilişkili faktörleri incelemek amaçlanmıştır.

**Gereç ve Yöntemler:** Çalışmamız kesitsel tipte bir çalışma olarak tasarlanmıştır. Bakım veren aile üyesinin sosyodemografik özellikleri, bakım bilgilerine ilişkin veri formları ve bakım yükünü ölçmek için Zarit bakım verme yükü ölçeği kullanılmıştır. Yaşlı bireylerin sosyodemografik özellikleri, günlük yaşam aktivitesini ve enstürmental günlük yaşam aktivitesini değerlendiren ölçek uygulanmıştır. Veriler Student-t-testi, Mann-Whitney U analizi, Varyans Analizi (ANOVA), Kruskal-Wallis varyans analizi ve doğrusal regresyon analizi kullanılarak analiz edildi; p <0.05 anlamlı kabul edildi.

**Bulgular:** Bakım verenlerin ortalama bakım yükü 31.95 ± 13.33 idi. Bakıcıların çoğu kadın, evli, eğitim düzeyi düşük, sosyal güvencesi olan, çocuk sahibi ve ev hanımıydı. Doğrusal regresyon analizi sonuçlarına göre, bakım veren aile ferdinin sağlık algısı, uyku kalitesi durumu, fiziksel ve ekonomik sorunların varlığı, yaşlıların günlük ve enstürmental yaşam aktive durumu ile bakım veren ailenin bakım verme yükü arasında istatistiksel olarak anlamlı bir ilişki bulunmuştur.

**Sonuç:** Bakım verenlerin fiziksel ve ekonomik sorunlarına yönelik destek hizmetlerinin sağlanması ve yaşlı bireyleri bağımsız kılmak için müdahaleler, bakım veren aile üyelerinin bakım yükünü önemli ölçüde azaltabilir.

**Anahtar Kelimeler:** Bakıcı yükü; bakıcılar; yaşlı; aile bakıcı; evde bakım

## Introduction

Alterations in the environment and lifestyle of the elderly population increase chronic diseases and the need for special care. [1] The burden of care of elderly is a prominent social issue in most countries. [2] The options towards the care of elderly are shaped by the social, economical, educational and cultural characteristics of the community. For example, in numerous societies, respect to the parents, family ties, economical restrictions lead the family members to take over the burden of care of elderly. [3]

The need of care for individuals may be defined as the need for help by other people as a result of their inability or difficulty when performing periodic or permanent activities due to their physical or mental disability or old age. Caregiving is a wide spectrum, and it is not possible to limit this to a single type of assistance. [4] Zarit et al. defined the concept of the burden as a measure of perception of its effects on emotional, physical, health, social life and material issues as a result of caring for their relatives. Instead of describing the burden of care as an inevitable negative result of caregiving, it defines it as the caregiver's subjective perception of the work performed for the needy persons or personal reactions to the behavior of the caregiver. [5]

Psychological, economical, and work-related problems, the disruption of family life, and physical health issues were reported as the consequences of the burden of care for the elderly people. [6]

In this study, we aimed to elucidate the burden of care on the family members, who provide care for individuals older than 65 years old, and related factors within the borders of Bornova district of Izmir, Turkey.

## Material and Methods

The population for this cross-sectional study was composed of individuals over 65 years old and their family members, who provide home care for them via the home care services of Bornova municipality. Bornova is a district located in the city center of Izmir. Bornova Municipality Health Services Department provides home care services with 1 physician and 2 nurses and other personnel upon request. Free home care services provided by Bornova Municipality for elderly adults include patient care and personal care assistance. We aimed at including all the elderly, who fulfils the criteria defined in this study without further sampling. The inclusion criteria consist of receiving homecare services of the municipality of Bornova, being at least 65 years old, and being cared of by a family member. On the other hand, receiving professional care and unwillingness to participate in the study were defined as the exclusion criteria.

Among them, the number of individuals who were over 65 years old and who benefit from the home care service of the municipality was 228.  In this study, the elderly and their caregivers living in 208 households (91%) were visited at their home and data were collected through face-to-face interviews.

The posthoc power analysis of this study was conducted by the G Power software. The following parameters, where the sample size was 208, the alpha error was 0.05, the effect size was 0.51 (Partial R2=0.34), resulted in 100% power.

Two separate data collection forms were created: caregiver and care receiver forms. The form of the caregiver consisted of sociodemographic characteristics, information on care status and care burden scale. The form for the care receiver included sociodemographic characteristics, health status, Katz's Activities of Daily Living (ADL) and Lawton and Brody's Instrumental Activities of Daily Living Index (IADL).[7, 8]

Zarit Burden Interview (BI) was used in the study. [5] It is a scale that provides one-dimensional and general measurement of maintenance load. Turkish validity and reliability study was conducted by İnci and Erdem in 2006. [4] The care burden scale is a self-report scale. In the scale, some questions address the relationship between caregiver's health, psychological well-being, financial status, social life, caregiver and elderly individual. The caregiver specifies the frequency of discomfort in each item on a 5-point Likert-type scale. The scoring of each item ranges from 0 to 4 points. In total, a minimum score of 0 and a maximum score of 88 is obtained, where the higher score indicates higher maintenance load. [4] Cronbach alpha coefficient of the scale used in this study is calculated to be 0.85.

Written permission was obtained from the Ethics Committee of Clinical Researches of Ege University Faculty of Medicine and Bornova Municipality to conduct the study.

In the evaluation of the data, version 20.0 of the SPSS statistical program was used. While evaluating the data, Student-t-test, Mann-Whitney U analysis, Variance Analysis, Kruskal-Wallis variance and linear regression analysis were performed for comparisons according to maintenance load. In statistical analyses, p <0.05 was considered significant.

## Results

First of all, 60.6% of the elderly individuals were women and the mean age was 80.2 ± 8.4 (min: 65, max: 105). The ratio of elderly caregivers was 32.2%. The ratio of elderly individuals with primary education level or lower was 89.9% and that of elderly individuals who had been cared for had at least two chronic diseases (multimorbidity) was 80.3%. The percentage of the elderly who received care and had a disability is 57.2%. Moreover, 63.5% of elderly individuals who received care were fully dependent or semi-dependent in terms of daily living activities. The ratio of the elderly who were fully dependent or semi-dependent in terms of instrumental daily living activities was 87%.

Among the family members taking care of the elderly individuals who participated in the study women make up the majority by 81.5%. The mean age of the caregivers was 57 ± 14.7 (min: 20, max: 90). The ratio of caring family members, who were married was 78.4%. In addition, 92.3% of the caregiving family members lived in urban centers. It was found that 10.1% of the caregiving family members were illiterate and 48.1% were primary school graduates. The ratio of the participating caregiving family members who were housewives 53.8% (Table 1).

| **Table 1.** Caregiver's sociodemographic characteristics | |
|---|---|
| | **n (%)** |
| **Gender** | |
| Female | 177(85.1) |
| Male | 31(14.9) |
| **Marital status** | |
| Married | 163(78.4) |
| Single | 30(14.4) |
| Widow | 15(7.2) |
| **Education status** | |
| Illiterate | 21(10.1) |
| Literate but not finished primary school | 15(7.2) |
| Primary school | 100(48.1) |
| Middle School | 23(11.1) |
| High school | 35(16.8) |
| College / University | 14(6.7) |
| **Social insurance** | |
| Yes | 196(94.2) |
| No | 12(5.8) |
| **Number of children** | |
| 0 | 25(12) |
| 1 | 23(11.1) |
| 2 | 87(41.8) |
| 3+ | 73(35.1) |
| **Residential area** | |
| Rural | 16(7.7) |
| Urban | 192(92.3) |
| **Working status** | |
| Housewife | 112(53.8) |
| Retired | 81(38.9) |
| Does not work because care for an elderly relative | 8(3.8) |
| Working (More than 30 hours) | 7(3.4) |
| **Relationship with the elderly** | |
| Daughter | 75(36.1) |
| Spouse | 70(33.7) |
| Bride | 38(18.3) |
| Son | 15(7.2) |
| Grandson | 9(4.3) |
| Other (mother-in-law of one's child) | 1(0.5) |

Besides, 43.3% of the caregiving family members were children of the elderly, 33.7% were spouses, 18.3% were brides and 4.3% were grandsons. Among the caregiving family members, 79.8% said they loved and cared because they had family ties with the elderly, 1.9% said that they cared because the elderly provide economic contributions.

The mean care burden score of the caregiving family members participating in the study was 31.95 ± 13.33 (min: 5, max: 65). When the average living status of caregiving family members and the burden of caregiving were examined,  It was found out that there was a statistically significant relationship between the burden of caregiving and home-sharing (p = 0.006), the elderly as a family responsibility (p = 0.012), spent during the day (p = 0.009),  health perception (p <0.001),  smoking status in the caregiving process (p <0.001), sleep quality (p <0.001), caregivers with physical health problems (p <0.001), economic problems (p <0.001) (Table 2). The mean care burden score of the caregivers of the elderly who were independent of IADL and ADL was found to be significantly lower than the other groups (p <0.001 / p = 0.002) (Table 3).

**Table 2.** Relationship between caregiver's variables and care burden score

| | n    (%) | Care Burden Score Mean±SD | P |
|---|---|---|---|
| **House Share†** | | | |
| Yes | 176(84.6) | 33.02±13.39 | 0.006 |
| No | 32(15.4) | 26.06±11.54 | |
| **Reason of the care ‡** | | | |
| I love/ Family bond* | 166(79.8) | 36.96±14.57 | |
| Family responsibility | 24(11.5) | 30.42±12.51 | 0.012 |
| No one else to care | 14(6.7) | 37.00±15.98 | |
| Economic contribution* | 4(1.9) | 47.50±12.12 | |
| **Daily time (Hour) ‡** | | | |
| 1-6 Hours* | 12(5.8) | 22.50±9.18 | |
| 7-12 Hours | 15(7.2) | 27.27±13.42 | 0.009 |
| 13-18 Hours | 9(4.3 ) | 26.22±12.59 | |
| 19-24 Hours* | 172(82.7) | 33.31±13.26 | |
| **Health perception ‡** | | | |
| Good* | 90(43.3) | 28.10±12.87 | |
| Moderate | 88(42.3) | 33.40±12.75 | <0.001 |
| Bad* | 30(14.4) | 39.23±12.87 | |
| **Smoke†** | | | |
| İncrease | 22(45.8) | 43.36±9.55 | <0.001 |
| No increase | 26(54.2) | 27.96±12.33 | |
| **Sleep quality †** | | | |
| No change | 97(46.6) | 25.39±10.86 | <0.001 |
| Decreased | 111(53.4) | 37.68±12.67 | |
| **Physical health problem†** | | | |
| Yes | 114(54.8) | 36.48±12.54 | <0.001 |
| No | 94(45.2) | 26.45±12.19 | |
| **Economic problems†** | | | |
| Yes | 67(32.2) | 37.99±12.75 | <0.001 |
| No | 141(67.8) | 29.08±12.66 | |

† Student t-test ‡ Kruskal-Wallis Varyans Analysis §ANOVA
* Pairwise comparisons statistically significant

**Table 3.** Relationship between elderly's ADL, IADL and care burden score

| | n (%) | Care Burden Score | P |
|---|---|---|---|
| Mean±SD | | | |
| ADL§ | | | |
| Fully dependent* | 51(24.5) | 33.27±11.57 | |
| Semi-dependent* | 81(39.0) | 34.96±13.53 | 0.002 |
| Indipendent* | 76(36.5) | 27.84±13.34 | |
| IADL ‡ | | | |
| Fully dependent* | 88(42.3) | 35.09±12.30 | |
| Semi-dependent | 93(44.7) | 31.92±13.76 | <0.001 |
| Indipendent* | 27(13.0) | 21.78±9.91 | |

‡ Kruskal-Wallis Varyans Analysis §ANOVA
* Pairwise comparisons statistically significant

In univariate analyses, linear regression analysis was performed with independent variables with a statistically significant difference between the caregiving burden score average of caregiving family members. There was a statistically significant relationship between health perception of the caregiving family member, sleep quality status, presence of physical and economic problems, ADL and IADL status of the elderly and caregiving burden of the caregiving family member. Significant variables were found to explain 34% of caregiving burden status of caregiving family members (Table 4).

**Table 4.** Linear regression model of care burden score

| Variables | | 95.0% CI for B | | | |
|---|---|---|---|---|---|
| | B | Lower Bound | Upper Bound | β | P |
| Health Perception | 3.68 | 0.46 | 6.90 | 0.14 | 0.026 |
| Sleep Quality Status | 7.94 | 4.31 | 11.56 | 0.30 | <0.001 |
| Physical Problems | 4.64 | 0.83 | 8.45 | 0.17 | 0.017 |
| Economic Problems | 4.89 | 1.46 | 8.31 | 0.17 | 0.005 |
| Daily Time (Hour) | 0.22 | -3.61 | 3.17 | 0.01 | 0.899 |
| House Share | 4.83 | -12.69 | 3.03 | 0.13 | 0.227 |
| Reason Of The Care | 1.89 | -0.69 | 4.48 | 0.09 | 0.151 |
| ADL | 3.60 | 0.59 | 6.59 | 0.21 | 0.019 |
| IADL | 3.84 | 0.38 | 7.30 | 0.20 | 0.030 |
| Constant | 22.50 | | | | |
| R² | | | | | 0.34 |

## Discussion

The burden of care for the elderly people are on the shoulders of the family members in Turkey, where the average age of the population is in a steady rise. In accordance with the previous publications on this subject, (75.5%-83.4%) in Bornova, which is one of the most populous districts of Izmir, most the caregivers are female members of the family (81.5%).

Elderly people living in Bornova district have heterogeneous characteristics and different socioeconomic conditions. Those with poor economic conditions, who are mostly cared for by their spouses or family members, request care from Bornova Municipality. The increasing age of caregiving spouses and the existence of their health problems especially increase the burden of care. [4,9] Care of the elderly is seen as the responsibility of women in both eastern and western societies in the world. [10] Caregivers provided 19.7% of the expenses of the elderly people who took part in the research. Caregiving family members who reported poor income perception constitutes 20.2% of participants. "Elderly with Statistics 2018" according to the report 15.5% of the elderly population in Turkey was determined to be poor. In general terms, the ratio of people in Turkey indicating the worst of the household income was 20.1%. In our study, the percentage of elderly individuals whose expenses are undertaken was similar to the percentage of poor elderly in the general population. [11] Ergin (2016) stated that the number of elderly who did not qualify for retirement in our country was high and the social support provided by the state was little and small. [12] This situation shows the need for a family support in meeting the expenses of the elderly individual and explains the high level of support given by the municipality.

The caregiving burden of the caregiving family members was $31.9 \pm 13.3$ points. The average maintenance score is quite high. In the literature, when the studies using Zarit's care burden scale are examined; (2016) in Ankara, Ünver et al. (2016) found that the caregiving burden of family members caring for the elderly was $38.7 \pm 13.7$. [9] In the Or's (2013) study, the mean care burden score was found out to be $32.63 \pm 15.72$. [13] In a study examining the care burden of caregivers for elderly people with dementia, covering eight European countries, the average care burden was found out to be 24.9. The long-term institutional care service network was effective in lowering the average care burden score in Europe. [14]

According to linear regression analysis, it was revealed that family members who perceive their health conditions as poor, have higher care burden than those who perceive them as good. In the literature, there are similar studies that express the relationship between health perception and care burden. [15,16] An individual with poor health perception may have higher difficulty in providing care and this may increase the burden of care.

The burden of care was found out to be significantly higher among the caregiving family members who had impaired sleep quality and who had little sleep. Zarit et al. (1980) stated that sleep disturbance is a difficult condition to tolerate during the caregiving process. [5] It may be thought that the sleep quality of the elderly individuals whose sleep patterns are disrupted and the lack of necessary resting time due to the intensity of caregiving may be a factor in the sleep quality of the caregiving family members. While the emotional burden of caregiving causes sleep disturbance, it is also understood that sleep disturbance may have a negative effect on care load and may have a double effect.

In this study, the caregiving burden of caregiving family members was found out to be statistically significantly more than those who had physical health problems in the care process. An increase in the relationship between caregiving and physical health problems was identified in the literature. [16,17] Physical health problems experienced by caregivers will lead to situations such as complicating or preventing them from performing tasks during caregiving. Also, Pinquart and Sörensen (2007) reported in their meta-analysis that caregivers with poor physical health were more burdened and depressed. [18]

When the relationship between the economic burden experienced by the caregiving family member and the care burden is examined; the care burden of caregivers with economic problems is higher than those without care. Salama and El-Soud's (2012) study in Egypt found out that the care burden was significantly lower in the caregivers of elderly people who indicated their financial status as adequate. [19] Yoon (2003) reported in Korea that caregiving burden decreased as the level of caregivers increased and that there was a negative relationship between them. [20] Caregivers suffer financially due to the elderly's treatment, care costs and the inability to continue work. Financial distress affects the physical and emotional health of the person negatively. The negative impact on physical and emotional health may lead to an increase in the burden of care for caring family members.

As the dependency of ADL and IADL increases, the burden of care increases. Also, there is a linear positive relationship between ADL and IADL scores and care burden score. In the literature, it is suggested that the burden of caregivers increases as the elderly dependency status of ADL and IADL increases. [21–23] The increase in the dependency of the elderly may lead to more physical and emotional difficulties for the caregiver and intensify the burden of caregiving.

## Limitations

The answers to the questionnaire are based on the notifications and subjective evaluations of the caregivers and the elderly (health, household income, sleep quality). The results cannot be generalized because the study was included the elderly and the caregiving family members receiving services from the municipality. There is a limitation in terms of causality from the cross-sectional design of the study. Few parts of the interviews with the caregiving family member had to be conducted in the presence of the elderly individual. This probably prevented caregivers to adequately articulate the difficulties experienced by caregivers.

## Conclusion

To sum up, the health perception, the sleep quality status, the presence of physical and economic problems, the ADL and IADL status of the elderly appear as the factors influencing the burden of care. Our data suggest that addressing these factors primarily will facilitate the mitigation of burden of care. Training of caregivers should be revised with a focus on their physical efforts and minimization of their problems. This will help to reduce both the potential physical problems and the burden of care. Burden of care should be mitigated by providing physical and mental health support to family members that are the caregivers of the elderly. Determining the economic situation of caregivers and providing financial support to caregivers will aid to reduce the burden of care. The elimination of the burden of care will enhance the quality of elderly care.

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