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Care burden and quality of life of home caregivers

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Abstract

This study was conducted to determine the care burden and quality of life of the primary caregivers of home care patients and to investigate the factors that affect them and the relationship between them. The study was designed as a descriptive, cross-sectional, and correlational study. The quality of life of caregivers who expressed that they had financial problems was lower than those who did not have financial problems ($p < 0.05$). A moderate negative relationship was found between caregivers' burden and quality of life ($r = -0.312$, $p < 0.001$). According to the findings of the study, it was determined that the increase in the care burden negatively affected the caregivers' quality of life.

Keywords: Quality of life, care burden, home care, caregiver, caregiving

Introduction

The most important reflection of the demographic transformation process is the growing need for long-term care in parallel with the growing elderly population. The advantages of home care services in meeting long-term care needs have led home care services to be preferred more than other service models [1,2]. Home care is a process that directly affects the life of the caregiver as well as the patient receiving care. For both economic and social reasons and cultural reasons, home care is accepted as the responsibility of the family. Therefore, the majority of caregivers are informal caregivers such as spouses, children, neighbours, etc [3]. The multidimensional response of the caregiver, who provides care for an elderly, a child, a family member with chronic illness or inadequacy or someone else, including physical, psychological, emotional, social and financial problems related to caregiving is called care burden [4]. In the literature, it is reported that especially after the informal caregiving process, care burden can lead to a decrease in physical health, social isolation, depression, burnout, anxiety and so on, and this situation adversely affects the quality of life of both the caregiver and the individual receiving care [5,6]. It is important to identify the difficulties that caregivers face and their quality of life in the caregiving process for the individual in need of care to receive better care and to provide support to caregivers.

Taking care of the patient and the caregiver as a whole in the home care process, evaluating the factors affecting the caregiver's quality of life and care burden and planning the service in this direction is of great importance in terms of the quality of the patient care as well as the maintenance of caregivers' well-being. This study was conducted to determine the care burden and quality of life of home care patients' primary caregivers and to investigate the factors that affect them and the relationship between them.

Materials and Methods

Population and Sample

In the present study, which was planned in the descriptive-relational design, not an ordinary sampling method was used, but it was aimed that all patients and caregivers were contacted. 383 of the 430 caregivers who were registered in the relevant units between May 26-July 26, 2017 met the inclusion criteria; and were included in the study. A total of 383 caregivers agreed to participate in the study and provided care for a patient for at least one year, and 383 patients who received care were included in the study.

Data Collection Tools

The data of the study was collected with the data collection form prepared by the researchers. The data collection form consisted of the patient and caregiver introductory form, the Barthel Index,

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the Zarit Caregiver Burden Scale (ZBCS), and the WHOQOL-Bref (TR) Quality of Life Scale.

Barthel index:

The scale, which was developed by Barthel and Mahoney in 1965 to determine the independence levels of patients in terms of performing their activities of daily living, was adapted to Turkish by Küçükdevece et al., and its validity and reliability test were performed. The scale consists of 10 items including activities of daily living such as eating, bathing, daily care, defecation, micturition, going to the bathroom, getting up from bed, climbing stairs, and walking. Scoring is performed between 0 and 100. Receiving 100 points means full independence, and 0 points mean full dependence. According to scale scores, patients with 0-20 points are considered as fully dependent, 21-61 points as highly dependent, 62-90 points moderately dependent, 91-99 points as mildly dependent, and 100 points as fully independent [7,8].

Zarit Caregiver Burden Scale

It was developed in 1980 by Zarit et al. to measure the level of burden experienced by caregivers of patients. It was adapted to Turkish by İnci [9,10]. The Likert-type scale consists of 22 items aiming at determining the effect of caregiving on the caregiver's life. 88 being the highest and 0 being the lowest score, a score of 0-20 indicates little or no burden, 21-40 indicates mild to a moderate burden, 41-60 indicates moderate to severe burden and 61-88 indicates severe burden.

WHOQOL-Bref (TR) Quality of Life Scale

The WHOQOL-Bref (TR) quality of life scale is designed to assess how the individual perceives his/her quality of life. The scale was developed by shortening the scale of the World Health Organization (WHOQOL) to 26 questions, and its validity and reliability test were performed by Eser et al. During Turkish validity studies, a national question was added, and the number of questions was increased to 27 while creating the WHOQOL-Bref-TR version. The scale, which includes closed-ended questions, consists of four domains including physical, psychological health, social relationships, and environment. General health status domain is composed of the questions 1, 2, and 3; physical health domain 3, 4, 10, 15, 16, 17 and 18; psychological health domain 5, 6, 7, 11, 19 and 26; social relationships domain 20, 21 and 22; environment domain 8, 9, 12, 13, 14, 23, 24, 25 and 27. The increase in the score received from the scale indicates that the quality of life increases [11].

The variables of the research

The dependent variable of the study is the mean score of the caregiving burden and the mean score of the caregiver's quality of life. The independent variables are the functional dependence levels of the patients, the socio-demographic characteristics of the patients and caregivers, and care-related characteristics of caregivers.

Evaluation of the Data

SPSS 21.0 (Statistical Package for Social Sciences) statistical software was used to analyze the data. Descriptive statistics were used for the frequency and percentages related to the general characteristics of the patients, the Barthel Index, and the caregiver introductory form. The mean, standard deviation, minimum, maximum, and percentage values of the WHOQOL-BREF (TR) Quality of Life Scale and Sub-dimensions were used as descriptive statistics. Variance analyzes were performed on the data for choosing the analysis method for the analysis of the research data. According to the Kolmogorov-Smirnov test, it was found that the data were distributed normally, and the variance was homogeneous according to the Levene test result ($p>0.05$). In this context, parametric statistical methods were selected. The relationship between the Barthel Index and Caregiver Burden Scale, WHOQOLBREF (TR) Quality of Life Scale, and Sub-dimensions were investigated with appropriate Pearson correlation analysis. The relationship between age and gender from demographic variables of the patients, and age, the degree of affinity to the patient, presence of another individual that he/she is obliged to take care, the duration of care for the patient, the status of getting help with care, whether there is a change in his/her daily life, experiencing financial problems, the change in home life, daily time devoted to carrying out the patient's work from demographic variables of the caregivers and the WHOQOL-BREF (TR) Quality of Life Scale and Sub-dimensions was assessed by independent samples t-test and ANOVA. Tukey test was used in all of the variances analyses to determine whether there was a significant difference between the groups. $p<0.05$ value was considered statistically significant.

Research Ethics

Before starting the study, the ethics committee approval was obtained from the Non-Interventional Clinical Research Ethics Board of Inonu University. The permission was received from the TR Ministry of Health, Turkey Public Hospitals Authority Malatya General Secretariat of the Association of Public Hospitals. The research was carried out with the patients and caregivers who agreed to participate in the research and were registered in the Home Health Services unit.

Results

The majority of the patients (70.0%) in the study were over 65 years old, female (57.4%), and married (51.7%). Most of the patients were receiving home care services due to stroke (24.5%). This was followed by diabetes (16.4%), cardiovascular diseases (11.2%), and cancer (9.9%). 72.1% of caregivers were female and the majority (48.3%) were between 40-59 years of age. Caregivers over the age of 60 constituted 23.2% of the caregivers. Formal caregivers accounted for only 1.8% of the surveyed care providers. 53.0% of the patients were cared for by their son/daughter and 26.1% by their spouses. 66.8% of caregivers did not receive help from any person for care. Caregivers' mean score of care burden was 42.82 ± 16.29 , whereas their mean score of quality of life was 81.88 ± 13.55 .

In Table 1, caregivers' mean score of care burden and quality of life and sub-dimension scores were compared according to age and gender of the patients. There was a statistically significant relationship between age, gender, and the caregiver's quality of life ($p < 0.05$). Although the mean scores of care burden were higher in those who provided care for female patients, the result was not statistically significant ($p > 0.05$). When caregivers' mean scores of care burden were examined according to age groups, it was found that the care burden was higher in the group under 2 years of age; this was followed by the 46-65 age group, and the difference between the groups was found to be statistically significant ($p < 0.001$). This difference was found to be between the groups under the age of 2 years and the other groups and also between the 3-18-year-old group and the other groups. In Table 2, the caregiver's mean score of care burden and quality

of life and sub-dimension scores were compared according to the dependence level in activities of daily living of the patients. There was a statistically significant relationship between the patient's dependence level in activities of daily living and the caregiver's quality of life ($p < 0.05$). The Barthel index was used to determine patients' level of independence in carrying out activities of daily living. According to the Barthel index, 35.7% of the patients were highly dependent and 39.6% were fully dependent. When caregivers' mean scores of care burden were examined according to the dependency level of patients, care burden was found to be higher in the fully dependent group; this was followed by the fully independent group, and the difference between the groups was statistically significant ($p < 0.001$). This difference was determined between all groups.

Table 1. Comparison of caregivers' mean scores of care burden and mean scores of quality of life and sub-dimension according to age and gender of the patients

Age	f	Care Burden	Physical Health Domain	Psychological Health Domain	Social Relationships Domain	Environment Domain	General Health Status	WHOQOL-BREF(TR)
Under 2 years old	4	88.00±2.56 ^a	14.00±5.23 ^a	12.00±2.15 ^a	6.00±3.57 ^{ab}	18.00±4.21 ^a	4.00±1.23 ^a	54.00±6.34 ^a
3-18 years old	7	20.00±15.08 ^b	22.14±1.34 ^b	19.00±2.23 ^{ab}	5.57±1.81 ^a	27.85±3.18 ^{ab}	6.71±0.48 ^b	81.28±5.87 ^b
19-45 years old	38	45.84±17.24 ^c	21.86±2.63 ^b	18.65±3.38 ^b	7.60±2.28 ^{ab}	28.78±4.04 ^b	5.52±1.10 ^{ab}	81.07±11.16 ^{ab,c}
46-65 years old	61	43.83±14.42 ^c	21.49±3.06 ^b	18.73±2.80 ^b	8.57±2.14 ^b	28.39±5.32 ^b	6.01±1.24 ^{ab}	83.21±12.33 ^c
66-85 years old	221	42.40±15.14 ^c	20.95±2.99 ^b	19.11±4.60 ^b	8.06±2.17 ^b	28.83±6.29 ^b	5.93±1.41 ^{ab}	82.56±13.56 ^{ab,c}
86 years old and older	49	40.16±14.75 ^c	20.08±3.29 ^b	18.38±4.19 ^b	7.77±2.74 ^{ab}	28.26±5.08 ^b	5.71±1.67 ^{ab}	80.20±15.60 ^{bc}
df	5	F=13.01 p<0.001	F=6.50 p<0.001	F=2.50 p<0.001	F=3.42 p<0.001	F=2.85 p<0.05	F=2.80 p<0.05	F=3.94 p<0.001
Patient's Gender								
Female	217	43.51±15.79	21.38±2.98	19.76±4.35	8.47±2.31	29.06±4.43	6.23±1.33	84.53±12.49
Male	163	41.89±16.94	20.42±3.14	17.58±3.60	7.36±2.08	27.86±7.23	5.39±1.34	78.37±14.13
df	378	t=0.95 p>0.05	t=2.98 p<0.001	t=5.27 p<0.001	t=4.88 p<0.001	t=1.85 p<0.001	t=6.06 p<0.001	t=4.41 p<0.001

Table 2. Comparison of caregivers' mean scores of care burden and mean scores of quality of life and sub-dimension according to some of the level of dependence in activities of daily living of patients

The level of dependence in activities of daily living according to the Barthel index								
Fully Dependent	149	49.97±17.24 ^a	20.73±3.74 ^a	18.71±5.66 ^{ab}	7.24±2.57 ^a	28.73±7.67	5.51±1.70 ^a	80.79±17.15 ^a
Highly Dependent	137	38.86±12.74 ^b	20.74±2.81 ^a	18.75±3.05 ^{ab}	8.26±1.97 ^a	28.04±4.22	5.99±1.15 ^b	81.20±11.36 ^b
Moderately Dependent	45	32.62±16.18 ^c	22.69±1.48 ^b	20.62±2.39 ^a	9.66±1.58 ^b	30.60±4.75	6.73±0.86 ^a	89.80±7.70 ^{ab}
Mildly Dependent	5	37.60±9.07 ^d	22.60±0.54 ^{ab}	18.60±1.67 ^{ab}	9.00±0.00 ^{ab}	27.20±0.44	5.80±0.44 ^{ab}	83.20±2.16 ^{ab}
Fully Independent	44	41.90±13.74 ^c	20.65±2.02 ^{ab}	17.65±2.02 ^b	7.86±1.74 ^a	27.47±3.07	5.86±1.01 ^{ab}	79.50±7.70 ^{ab}
df	4	F=15.94 p<0.001	F=4.27 p<0.001	F=3.02 p<0.05	F=12.00 p<0.001	F=2.13 p>0.05	F=7.47 p<0.001	F=4.69 p<0.001

*There was a statistically significant difference between the groups with different superscript

Table 3 presents the comparison of caregivers' mean scores of care burden and mean scores of qualities of life and sub-dimension according to some characteristics of the caregivers. There was a significant relationship between caregiver's age, gender, daily life, and home life changes, experiencing financial problems and care burden ($p < 0.05$). A significant relationship was found between the

caregiver's age, gender, degree of affinity to the patient, daily life and home life changes, experiencing financial problems, and the status of getting help with care and the caregiver's quality of life ($p < 0.05$). In this study, mean scores of care burden give providing care for their parents were higher than those of caregivers providing care for their spouses or siblings, but the results were not

statistically significant ($p>0.05$). The psychological health domain means the score was the lowest in caregivers caring for their spouses ($p<0.05$). The group with the lowest mean score of quality of life scale was the caregivers caring for their child ($p<0.05$).

As shown in Table 4, there was a negative correlation between

care burden and WHOQOL-BREEF (TR) quality of life scale ($r=-0.312$, $p<0.001$). Also, as the care burden increased, the physical health domain ($r=-0.320$, $p<0.001$), social relationships domain, environment domain ($r=0.255$, $p<0.001$), psychological health domain (-0.145 , $p<0.001$), general health domain (-0.341 , $p<0.001$) scores decreased, and the results were statistically significant.

Table 3. Comparison of caregivers' mean scores of care burden and mean scores of quality of life and sub-dimension according to some characteristics of the caregivers.

Age	f	Care Burden	Physical Health Domain	Psychological Health Domain	Social Relationships Domain	Environmen Domain	General Health Status	WHOQOL-BREEF(TR)
20-39	106	46.81±14.99 ^a	21.27±3.61	20.35±5.40 ^a	8.11±2.37 ^a	29.45±4.49 ^a	6.35±1.40 ^a	85.24±13.38 ^{ab}
40-59	185	41.10±17.01 ^b	21.08±2.92	18.68±3.38 ^b	8.32±2.10 ^a	28.83±7.04 ^a	5.85±1.36 ^b	82.229±13.92 ^b
Over 60 years of age	89	41.64±15.61 ^{ab}	20.37±2.66	17.31±3.32 ^c	7.15±2.34 ^b	26.93±3.93 ^b	5.32±1.27 ^c	77.05±11.58 ^a
df	2	F=4.521 p<0.05	F=2.28 p>0.05	F=13.88 p<0.001	F=8.42 p<0.001	F=4.98 p<0.001	F=13.88 p<0.001	F=9.38 p<0.001
Caregiver's Gender								
Female	273	43.82±17.55	20.50±3.24	18.46±4.40	7.81±2.26	28.06±6.18	5.71±1.44	80.32±13.98
Male	107	40.26±12.25	22.16±2.24	19.79±3.38	8.45±2.26	29.79±4.57	6.28±1.20	85.88±11.52
df	378	t=-2.23 p<0.05	t=5.63 p<0.001	t=2.76 p<0.001	t=2.49 p<0.05	t=2.57 p<0.05	t=3.60 p<0.001	t=3.65 p<0.001
The degree of affinity with the patient								
A/B	24	37.08±20.94	21.75±2.9	18.04±3.16 ^{ab}	6.95±1.8 ^a	27.52±4.2	5.58±1.2 ^{ab}	79.16±10.9
K/O	200	44.47±15.46	20.93±3.2	19.33±4.81 ^a	8.13±2.2 ^{ab}	28.58±4.9	6.12±1.4 ^a	82.85±14.0
Spouse	100	41.80±17.42	20.82±2.3	17.70±2.93 ^b	7.51±2.3 ^{ab}	28.36±7.4	5.42±1.2 ^{ab}	79.59±12.6
Sibling	16	41.43±19.02	21.75±4.7	19.93±5.20 ^{ab}	9.06±3.0 ^b	29.38±7.2	5.81±1.6 ^{ab}	84.00±20.6
Other	40	41.12±12.34	20.71±3.2	19.17±2.90 ^{ab}	8.70±1.6 ^b	29.12±5.4	5.92±1.2 ^b	83.60±10.2
df	4	F=1.499 p>0.05	F=0.762 p>0.05	F=3.13 p<0.05	F=4.53 p<0.001	F=0.35 p>0.05	F=4.60 p<0.001	F=1.47 p>0.05
Getting help while providing care								
Yes	127	42.15±13.59	21.52±3.20	19.45±3.57	8.29±2.04	29.40±4.38	6.09±1.56	84.56±12.84
No	253	43.15±17.51	20.68±2.99	18.52±4.43	7.84±2.38	28.11±6.40	5.76±1.29	80.54±13.72
df	378	t=-0.610 p>0.05	t=2.46 p<0.05	t=2.19 p<0.05	t=1.79 p>0.05	t=2.26 p<0.05	t=2.19 p<0.05	t=2.81 p<0.001
Changes in his/her daily life								
Yes	228	45.84±13.68	21.29±2.93	19.53±4.63	8.92±2.56	29.71±6.16	5.96±1.49	84.06±13.82
No	152	38.28±18.72	20.49±3.25	17.77±3.12	8.10±1.78	26.80±4.80	5.74±1.22	78.63±12.48
df	378	t=-4.52 p<0.001	t=2.40 p<0.05	t=4.05 p<0.001	t=-0.77 p<0.05	t=4.84 p<0.001	t=1.49 p>0.05	t=3.89 p<0.001
Changes in his/her home life								
Yes	206	46.80±13.56	21.51±2.96	19.93±4.72	8.16±2.68	30.19±6.22	6.00±1.51	85.38±14.08
No	172	38.01±18.04	20.28±3.09	17.48±2.95	7.75±1.64	26.56±4.65	5.71±1.25	77.55±11.57
df	376	t=5.39 p<0.001	t=3.91 p<0.001	t=5.83 p<0.001	t=1.78 p>0.05	t=6.22 p<0.001	t=1.93 p>0.05	t=5.83 p<0.001
Experiencing financial problems								
Yes	127	50.84±13.12	21.15±2.99	19.42±5.85	8.58±2.77	28.60±5.08	5.49±1.59	81.82±14.91
No	253	38.79±16.27	20.87±3.13	18.53±3.00	8.20±1.96	28.52±6.16	6.06±1.25	81.92±12.84
df	378	t=7.24 p<0.001	t=0.81 p>0.05	t=1.93 p>0.05	t=-2.50 p<0.05	t=0.13 p>0.05	t=-3.78 p<0.001	t=-0.06 p<0.05

*There was a statistically significant difference between the groups with different superscript.

** M/F: Mother/Father

D/S: Daughter/Son

Table 4. Correlation table between mean scores of care burden and mean scores of quality of life and sub-dimension.

Scales		Physical Health Domain	Psychological Health Domain	Social Relationships Domain	Environment Domain	General Health Status	WHOQOL-BREF(TR)
Care Burden	r	-0.320	-0.145	-0.308	-0.255	-0.341	-0.312
	p	p<0.001	p<0.001	p<0.001	p<0.001	p<0.001	p<0.001

Discussion

As a reflection of the demographic transformation process, the need for home care in recent years has increased. In this study, the majority of patients receiving home care were female, and over 65 years of age. The findings of the study are similar to those of other studies carried out on home care patients, and this can be explained by the increased incidence of chronic diseases with aging and the fact that the average life expectancy of women after birth is longer than men [12,13]. In studies conducted with home care patients in the world and our country, chronic diseases such as stroke, diabetes, cancer, and cardiovascular diseases and Alzheimer's disease are the main reasons for patients to receive care at home (65,67,68). The patients included in the study were receiving home care services mostly due to stroke, diabetes, cardiovascular diseases.

The mean age of caregivers in the study was 49.26±14.23, and the majority of caregivers were between 40 and 60 years of age. In studies conducted in our country and abroad, it is reported that women constitute a significant proportion of caregivers [14,15]. Similarly 72.1% of the caregivers were female in our study. This may be because, in almost all societies, patient care is perceived as a task that women can do naturally and easily.

Similar to other studies in the literature, care was given to patients in the study by mostly patients' sons and daughters (53.0%) and their spouses (26.1%) [10,16-8]. In their study, Tuna and Olgun reported that the degree of affinity of caregivers to the patient varied between countries and that caregivers in Taiwan were the spouses of the patients, whereas caregivers in the United States were the children of the patients [19].

In this study, the mean score of the Caregiver Burden Scale was found as 42.82±16.29. According to this result, caregivers in the study had moderate/severe caregiving burden. Similarly to our study, in Bekdemir's study with bed-bound patients receiving home care, the mean score of Caregiver Burden Scale was found as 43.56±15.05 [17]. In their study with stroke patients, Mollaoğlu et al. reported the mean score of the Caregiver Burden Scale as 33.02±15.92 [16]. In the study of Öner with oncology patients, the mean score of the Caregiver Burden Scale was reported as 32.11±12.44 [20].

In this study, the WHOQOL-BREF (TR) quality of life scale was used to measure the caregivers' quality of life. The caregivers' mean score of quality of life in the study was 81.9±13.5; when the caregivers' quality of life was evaluated according to each sub-domain, it was found as 21.0±3.08 in the physical health domain, 18.8±4.1 in the psychological health domain, 8.0±2.3 in

social relationships domain and 28.5±5.8 in environment domain. In their study with caregivers caring for patients with bipolar disorder, Çoban et al. reported the mean score of quality of life as 79.8±10.8. When we compared our study with the sub-dimensions of the WHOQOL-BREF (TR) quality of life scale, the mean scores of physical, psychological health, social relationships, and environment domains were higher than our study [21].

Similar studies in the literature report that the caregiver's quality of life is reduced as care burden increases [21-25]. For example, in the study of Ribe et al. in Spain, a strong negative correlation was found between care burden and the quality of life [26]. In our study, a negative moderate relationship was found between care burden and WHOQOL-BREF (TR) quality of life scale, which is in line with the literature. Also, as care burden increased, scores in physical, psychological health, social relationships, environment, and general health domain decreased, and the results were statistically significant. As a result, it was determined that the increase in the care burden decreased the caregiver's quality of life.

When the mean score of caregivers' care burden was examined according to the dependency level of the patients, it was found that the difference in the care burden was higher in the fully dependent group, and this was statistically significant. In their study to determine the care burden of caregivers of patients who were given home care, Taşdelen and Ateş reported that the increase in dependency levels of the patients could increase the care burden [27]. This may be due to the increased level of dependency leading to an increase in the care needs of the individual and, consequently, to the increased role of caregiver inpatient care.

When the mean scores of the caregiver burden were compared with the genders of caregivers, the mean score of the Caregiver Burden Scale was higher in female caregivers, and the difference was statistically significant (p<0.05). Also, female caregivers had lower quality of life scores than males (p<0.001). In contrast to our study, in some studies in the literature, the gender of the caregiver was reported to not affect the care burden [17,22]. However, similar to our study, they reported that gender had an effect on the care burden and that male caregivers had less care burden [28-29]. The reason for the fact that the female caregivers' mean score of care of burden is higher than that of men in the study can be explained by the fact that women have more household tasks and social responsibilities than men, in addition to providing care.

When the caregivers' mean scores of care burden were compared according to age groups, it was observed that the mean scores of the Caregiver Burden Scale were higher in the caregivers between the ages of 20 and 39 years, and this was followed by

the caregivers over the age of 60 ($p<0.05$). Also, the quality of life scores of surveyed caregivers over 60 years of age was found to be lower than those of other age groups ($p<0.001$). Although there are studies in the literature reporting that the care burden increases with the age of the caregiver, similar to our study, Bekdemir reported that the care burden between the ages of 20 and 25 is high and that it was followed by caregivers over 65 years of age [17,24]. Zaybak et al. reported that there was no correlation between the age of the caregiver and the care burden [18]. The reason for the high care burden in the young caregiver's group may be due to lack of experience, but also due to their inability to spare enough time for their social lives. The mean score of care burden is high in the elderly group may be caused by the caregiver's quality of life decreasing in parallel with the addition of chronic health problems due to old age. In the literature, it is reported that the presence of health problems of the caregivers may lead to an increase in the difficulty experienced by the caregiver during the care, and thus cause a higher care burden [30-32].

Due to the cultural structure of Turkish society, caregivers generally care for patients who are first-degree relatives, such as spouses or children. In the literature, it is reported that the care burden is related to the degree of affinity and that it is lower when the care provider is a first-degree relative due to the cultural perception [27,33]. The mean scores of care burden of caregivers who provide care for their parents were higher compared to caregivers who provide care for their spouses or siblings ($p>0.05$). In a study by Karahan, it is reported that the highest level of care burden is experienced by the caregivers caring for their child [34]. The changing family structure in recent years has increased the responsibility of the women in her constant role as a permanent caregiver at home with her changing social roles, as women become more involved in work life, and as a result, in care for parents, in particular, it has led people to turn to institutional care, which has been perceived as normal. In Karahan's study, caregivers of their children have the lowest mean score in the psychological health domain, which is a sub-dimension of quality of life. In our study, the mean score of the psychological health domain was the lowest in the caregiving spouses. The mean score of quality of life scale was the lowest in the group who cared for their child.

In the literature, it is reported that the presence of social support in the caregiving process has important effects on caregivers and that caregivers who receive support in the care process are reported to have lower care burden scores [20,35]. When the mean scores of caregivers' care burden were compared according to whether they received help in the care process, it was found that mean scores of care burden of the individuals who did not receive help were higher than the individuals who received help, and that the difference between the groups was not statistically significant. When the quality of life of caregivers was examined according to whether they received help in the care process, it was found that mean scores of quality of life of the individuals who received help were higher than the individuals who did not receive help and that the difference between the groups was statistically significant ($p<0.001$). Similar to our study, Karahan, in his study, found that those who received care support and those who found the received help sufficient were more likely to have a higher quality of life scores than the other groups [34].

The caregiving process can cause changes in both the caregiver's daily life and home life. Inevitably, the person who goes out of his/her usual life routine and undertakes different social responsibilities will experience the problem of adaptation under these circumstances. In this study, the mean scores of care burden of caregivers with daily life and home life changes were found to be higher than those without change. On the other hand, the mean scores of quality of life were significantly higher in caregivers who had daily and home life changes. The mean scores of the environment and social relationships domains in particular in the quality of life scale were higher in those who had changes in their home life and daily life.

In the caregiving process, many caregivers are forced to quit. As a result, the increasing expense despite decreasing income may cause people to experience financial problems. The mean scores of care burden of caregivers who stated that they had a financial problem were higher, and their quality of life in physical, psychological health, social relationships, and environment and overall quality of life mean scores were found to be lower than those who did not have financial problems. The result is consistent with the literature [36,37].

In conclusion, it was determined that the increase in the care burden decreased the caregiver's quality of life. Countries should develop new care models that are unique to their conditions by taking into account the needs of the caregivers, and in this respect, opening the way for pilot studies can reduce caregivers' care burden and improve their quality of life.

Conflict of interests

The authors declare that they have no conflict of interest and any financial disclosures.

Financial Disclosure

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Ethical approval

Before starting the study, the ethics committee approval was obtained from the Non-Interventional Clinical Research Ethics Board of Inonu University.

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