




Identifying the caregiver burden for the elderly population aged ≥ 85 years in a province

Bir ilde 85 yaş ve üzeri nüfusa bakım verenlerin bakım yükünün tespiti

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Abstract

Aim: The number of elderly individuals aged ≥ 85 is steadily increasing. With this increase, the care needs of the elderly and the caregiver burden are increasing. The present study aimed to identify the caregiver burden providing care to a population aged ≥ 85 , as well as its associated factors.

Materials and Methods: The universe of this cross-sectional study was 3741 individuals over 85 years of age living in Burdur province. $N = 3741$ subjects, $p = 0.50$; $q = 1-p$; $t = 1.96$; $d = 0.05$ and the sample size is calculated as 348 persons. Since Family Medicine Information System will be used in the selection of the sample, the number of elderly people to be taken from each family physician was found by dividing the number of the family physician; accordingly, the number of elderly people per family physicians were found 4.4 (348/79 = 4.4 people). However, considering the possibilities of death or hospitalization of the elderly, it was decided to recruit 5 people from each family physician and the number of samples was accepted as 395. Five elderly were determined by randomization. In statistical analysis, the t-test and analysis of variance were applied on scale scores. Multivariate analysis was performed using forward linear regression method to determine the reasons affecting the care burden. Results: The mean age of the elderly population was 88.0 ± 2.5 years. The mean age of the caregivers was 60.3 ± 13.1 years, and 84.8% of them were women. The mean Zarit Caregiver Burden Scale score of the caregivers was 35.49 ± 18.08 . The dependence of the elderly individual, a poor overall health perception of the caregivers, and residence in the same house with the elderly individual were observed as the factors that increased the care burden ($p = 0.004$ and $p = 0.004$, $p < 0.001$ and $p = 0.026$).

Conclusion: Of the elderly, 68.4% needed care. The dependence of the elderly individual, a poor overall health perception of the caregiver, and residence in the same house with the elderly individual increased the care burden.

Keywords: Aged, caregiver burden, zarit caregiver burden scale.

Öz

Amaç: 85 yaş ve üzeri yaşlı birey sayısı giderek artmaktadır. Bu artışla birlikte yaşlıların bakım ihtiyaçları ve bakım veren yükü artmaktadır. Bu çalışma, 85 yaş üstü nüfusa bakım verenlerin yükünü ve bununla ilişkili faktörleri tanımlamayı amaçlamıştır.

Gereç ve Yöntem: Bu kesitsel tipteki bu çalışmanın evreni, Burdur ilinde yaşayan 85 yaş üstü 3741 kişidir. $N = 3741$ kişi, $p = 0,50$; $q = 1-p$; $t = 1,96$; $d = 0,05$ olup örnek büyüklüğü 348 kişi olarak hesaplanmıştır. Örneklem seçiminde Aile Hekimliği Bilgi Sistemi kullanılacağından, her aile hekiminden alınacak yaşlıların sayısı aile hekimi sayısının bölünmesiyle bulunmuştur.

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Application date: 02.04.2020 Accepted: 29.09.2020

Buna göre, Aile hekimi başına düşen yaşlı sayısı 4,4 olarak tespit edilmiştir (348/79 = 4,4 kişi). Bununla birlikte, yaşlıların ölüm ve hastaneye yatış olasılıkları göz önüne alındığında, her aile hekiminden 5 kişinin alınmasına karar verilmiş ve örneklem sayısı 395 olarak kabul edilmiştir. Beş yaşlı randomizasyon ile belirlenmiştir.

İstatistiksel analizde ölçek puanlarına t testi ve varyans analizi uygulanmıştır. Bakım yükünü etkileyen nedenleri belirlemek için ileri doğrusal regresyon yöntemi kullanılarak çok değişkenli analiz yapılmıştır.

Bulgular: Yaşlı nüfusun ortalama yaşı $88,0 \pm 2,5$ dir. Bakım verenlerin yaş ortalaması $60,3 \pm 13,1$ ve %84,8'i kadındır. Bakıcıların ortalama Zarit Bakım Yükü Ölçeği puanı $35,49 \pm 18,08$ 'dir. Bakım yükünü artıran faktörler olarak yaşlı bireyin bağımlılığı, bakıcıların genel sağlık algısının zayıf olması ve aynı evde yaşlı bireyin oturması gözlenmiştir ($p = 0,004$ ve $p = 0,004$, $p < 0,001$ ve $p = 0,026$).

Sonuç: Yaşlıların %68,4'ünün bakıma ihtiyacı bulunmaktadır. Yaşlı bireyin bağımlılığı, bakıcının genel sağlık algısının zayıf olması ve yaşlı bireyle aynı evde oturması bakım yükünü artırmaktadır.

Anahtar Sözcükler: Yaşlı, bakım yükü, zarit bakım yükü ölçeği.

Introduction

According to the data from the WHO, the mean life expectancy at birth for both sexes was 68 years in 1990 and has reached 74 years in 2013. Demographic shift is observed in Turkey that is similar to the situation in several other countries worldwide. In the 1940s, the life expectancy for women and men was 33 and 30 years, respectively. Today, the mean life expectancy for men is 75.3 years and that for women is 80.7 years (1). The number of elderly individuals is steadily increasing. The number of individuals aged >80 years globally was reportedly 125 million in 2015 (2). In several developing countries, including Turkey, it is reported that the population aged >80 years will increase four-fold by 2050 (3). In Turkey, the number of elderly individuals aged >85 years was reported to be 595,353 in 2017 (4).

Although life expectancy has increased, with poor health and reduced mobility, need for care is emerging. Elderly care has become the most important social issue (1). A significant proportion of the elderly population aged >80 years are individuals with the highest level of care needs because of their diseases or other reasons (6).

“Care” is defined as the planned, regular contribution and support provided externally to the individual with physical, psychological, social, and economic deficiencies in sustaining his/her life and order in society at an adequate level to sustain his/her daily life. Care services comprises a wide spectrum of services including health care (medication intake, treatment, monitoring, etc.), personal care (bathing, feeding, toileting, dressing, etc.), and mobilization as well as coordinating the services received by the patient along with shopping and housekeeping, money management, financial assistance, and sharing the same house (7, 8).

In the early 1960s, the concept of “burden” was defined by Grad and Sainbury for the first time in scientific literature for family members who care for their relatives with psychological illnesses in their homes (9). The concept of burden includes “negative objective and subjective outcomes, caused by the care provided by a caregiver, such as psychological distress, physical health issues, economic issues, and social issues as well as the deterioration of family relations and the sense of not having control” (9). Although caregivers are striving to create an appropriate care and supportive environment for the elderly, their health and social conditions are affected by this process (1).

Care is influenced by cultural values and norms. In several societies, family members are obliged to care for their elderly owing to various reasons such as filial piety, strong family ties, or social pressure and financial concerns (6). In the Turkish culture, the members of the family are primarily responsible for care. Moreover, this is expected by the elderly. According to the “Family Structure Survey” conducted by the Turkish Statistical Institute, 51.3% of the individuals aged ≥65 years and older desired to live with their children when their preferences for residing when they are too old to care for themselves were examined according to age groups (10).

Materials and Methods

This cross-sectional study was conducted between May and August 2017 in Burdur province and its districts. The population of the study comprised 3,741 individuals aged >85 residing in Burdur province (11). $N = 3741$ subjects, $p = 0.50$; $q = 1-p$; $t = 1.96$; $d = 0.05$ and the sample size is calculated as 348 persons. Since Family Medicine Information System will be used in the selection of the sample, the number of elderly people to be taken from each family physician was found by dividing the number of

the family physician; accordingly, the number of elderly people per family physicians were found to 4.4. (348/79 = 4.4 people). However, considering the possibilities of death of the elderly and hospitalization, it was decided to recruit 5 people from each family physician and the number of samples was accepted as 395. 5 elderly were determined by randomization. A total of 257 family members who took care of these elderly individuals participated in the study. The elderly individuals who reside in a nursing home and have a paid caregiver were not included in the study.

For the collection of study data, a questionnaire prepared by the authors that comprised Zarit Caregiver Burden Scale (ZCBS), Katz Index of Activities of Daily Living (ADL), and Lawton and Brody Instrumental Activities of Daily Living (IADL) Scale was administered to the caregivers of individuals aged >85 years who agreed to participate in the study by giving verbal consent. The questionnaire inquires the Introductory Characteristics of Elderly, General Health Characteristics of Elderly, Activities of Daily Living of Elderly, Introductory Characteristics of Caregivers, and Care-related characteristics of caregivers.

After obtaining the necessary permits from the Public Health Directorate and Burdur Governorship, the data was collected by the midwives and nurses who worked in the Burdur Central Community Health Center between May and August 2017 using a face-to-face interview approach. The data of the research was evaluated using SPSS program version 15.0. Descriptive statistics included number, percentage, mean, standard deviation, and minimum and maximum values. In statistical analysis, the t-test and analysis of variance were applied on scale scores. A p value of <0.05 was considered statistically significant. Bonferroni analysis was performed to determine the group that caused the difference. To determine the reasons affecting the caregiver's burden, multivariate analysis was performed using the forward linear regression method.

To conduct the study, ethics committee approval was obtained from Mehmet Akif Ersoy University Non-Interventional Clinical Research Ethics Committee, and the study permit was obtained from Burdur Governor's Office and Burdur Public Health Directorate.

Results

Of the targeted study sample, 95.2% (376 individuals) was included. The mean age of the elderly in the study was 88.0 ± 2.5 years, and 79.5% were in the 85–89 age group. Of the elderly population, 77.4% reported a chronic disease and the most common chronic disease (43.6%) was hypertension; 14.6% did not use any orthotic devices.

Although 68.4% of the elderly individuals (257) received care from someone else, 31.6% did not need care from another person.

Of the caregivers, 52.9% were the children of the elderly individuals. The mean age of caregivers was 60.3 ± 13.1 years, and 84.8% of them were female.

The burden of the caregivers is shown in (Table-1). The mean ZCBS score was 35.49 ± 18.08, with a minimum score of 5 and a maximum score of 82 (Table-2). Shows the distribution of mean ZCBS scores according to the characteristics of the elderly (Table-3). Shows the distribution of the mean ZCBS scores according to the characteristics of the caregiver.

It was observed that the caregiver burden was higher in men than in women, in caregivers who were illiterate compared with those who were secondary school/higher education graduates, and in single/divorced/widowed caregivers compared with the married ones as well as in caregivers living in houses where ≥3 individuals reside together and in caregivers who reside in the same house with the elderly.

A model was created including the lack of income, such as rent and profit; receiving old-age pension; being dependent or partially dependent according to the Katz ADL and Lawton/Brody IADL indices; sex, educational status, and marital status of the caregiver; the number of individuals living at home; and residing with the elderly individual. The results of multivariate analysis for the factors affecting the caregiver burden are presented in (Table-4).

Dependence according to the ADL and IADL indices; poor general health perception of the caregiver; and residing in the same house with the elderly individual were identified as the factors that increase the care burden (p = 0.004 and p = 0.004, p <0.001, and p = 0.026, respectively).

Table-1. Burden of the caregivers.

Absent n (%)	Mild n (%)	Moderate n (%)	Heavy n (%)	Total n (%)
69 (26.8)	99 (38.5)	63 (24.6)	26 (10.1)	257 (100.0)

Table-2. Distribution of the mean caregiver burden scale scores according to the characteristics of elderly.

	n	%	X ± ss	Test value	P
Age group					
85–89 years	194	75.5	34.77 ± 17.63	0.624	0.537
90–94 years	56	21.8	37.62 ± 19.88		
≥95 years	7	2.7	38.28 ± 16.44		
Sex					
Female	167	65.0	36.13 ± 18.08	0.781	0.436
Male	90	35.0	34.28 ± 18.12		
Educational status					
Illiterate	207	80.5	36.33 ± 18.01	2.350	0.127
Elementary and above	50	19.5	31.98 ± 18.14		
Marital status					
Married	78	30.3	33.80 ± 17.47	0.984	0.326
Widowed /divorced	179	69.7	36.22 ± 18.34		
Health insurance					
Present	243	94.5	30.28 ± 18.61	1.108	0.269
Absent	14	5.5	35.79 ± 18.05		
Pension of his/her own					
Present	70	27.3	34.75 ± 17.85	0.397	0.692
Absent	187	72.7	35.76 ± 18.21		
Pension of his/her spouse					
Present	83	32.3	34.30 ± 17.51	0.727	0.468
Absent	174	67.7	36.05 ± 18.37		
Income (rent, profit, etc.)					
Present	36	14.0	29.69 ± 17.20	2.087	0.038
Absent	221	86.0	36.43 ± 18.09		
Old age/disability pension					
Present	78	30.4	39.15 ± 19.38	2.159	0.032
Absent	179	69.6	33.89 ± 17.31		
Children's aid					
Present	92	35.8	35.46 ± 18.78	0.015	0.988
Absent	165	64.2	35.50 ± 17.74		
Social welfare					
Present	53	20.6	36.00 ± 16.32	0.230	0.818
Absent	204	79.4	35.35 ± 18.55		
Chronic disease					
Present	56	21.8	34.25 ± 18.00	0.579	0.563
Absent	201	78.2	35.83 ± 18.14		
Number of drugs used					
≤4	116	57.7	33.88 ± 17.20	1.713	0.088
≥5	85	42.3	39.90 ± 20.47		
Use of orthotic devices					
Yes	219	85.2	34.84 ± 18.99	1.366	0.173
No	38	14.8	39.18 ± 17.21		
Dependency based on Katz ADL Index					
Completely dependent	12	4.7	47.00 ± 16.06	17.127	0.000
Partially dependent	48	18.7	46.70 ± 18.89		
Independent	197	76.6	32.05 ± 18.08		
Dependency status based on Lawton and Brody IADL Index					
Completely dependent	38	14.8	45.68 ± 20.43	16.178	0.000
Partially dependent	154	59.9	36.77 ± 16.92		
Independent	65	25.3	26.49 ± 15.30		

Table-3. Distribution of the mean ZCBS scores according to the characteristics of the caregiver.

	n	%	X ± ss	Test value	P
Caregiver's relation to the elderly (n = 257)					
Spouse	48		32.33 ± 17.76	0.854	0.427
Child	136		36.20 ± 17.35		
2 nd degree relative (daughter-in-law, grandchild, sister)	72		35.90 ± 19.54		
Age group					
<65 years	176		35.93 ± 17.87	2.118	0.122
65–84 years	71		36.00 ± 18.85		
≥85 years	10		24.00 ± 13.26		
Sex					
Female	218		36.83 ± 18.59	2.867	0.004
Male	39		27.94 ± 12.69		
Educational status					
Illiterate	69		38.68 ± 18.62	3.387	0.035
Elementary	141		35.78 ± 17.77		
Secondary and higher	47		29.91 ± 17.28		
Marital status					
Married	210		34.37 ± 17.98	2.110	0.036
Single/Divorced/Widowed	47		40.48 ± 17.87		
Employment Status					
Employed	41		33.02 ± 16.86	0.952	0.342
Unemployed/retired	216		35.95 ± 18.31		
Number of people living at home					
≤2	151		32.88 ± 17.61	2.797	0.006
≥3	106		39.20 ± 18.18		
Residing with the elderly					
Yes	180		37.88 ± 18.24	3.305	0.001
No	77		29.89 ± 16.51		
Duration of living with the elderly					
<10 years	71	39.4	39.76 ± 17.05	1.243	0.266
≥10 years	109	60.6	36.66 ± 18.95		
Time spent together (h/day)					
<8 h	127	70.6	36.88 ± 17.22	1.141	0.255
≥8 h	53	29.4	40.28 ± 20.45		

Table-4. Forward linear regression.

Independent variable	B	Std. error	Beta	t	Sig.
Katz ADL Index	-5.468	1.856	-0.189	-2.946	0.004
Lawton and Brody IADL Index	-6.200	2.124	-0.187	-2.919	0.004
General health perception of caregiver	6.859	1.209	0.310	5.672	<0.001
Living in the same house with the elderly	-4.889	2.179	-0.124	-2.244	0.026

Discussion

The number of elderly individuals is rapidly increasing worldwide as well as in Turkey and in our province. In Burdur, 31.6% of the elderly population can maintain their own life without needing care. However, 68.4% of the elderly needed care. As a reflection of the high proportion of the elderly in the province, 42.8% of caregivers are individuals aged ≥ 65 years.

We found that 10.1% of caregivers have a substantial care burden, which can cause physical and mental disorders. Identifying the burden is essential to increase the quality of care.

The activities in which caregivers are challenged the most are those requiring physical performance (i.e. mobilization, toileting, bathing). As caregiver's health perception worsens, the care burden increases.

In our study, the mean ZCBS score was 35.49 ± 18.08 , and although it is similar to the studies on caregivers for the chronic patients in literature (13, 14), it appears higher than others (1, 5, 15, 16). Due to the gradual decline in physiological functions with age, additional assistance is required to meet daily needs. In addition, the duration of caregiving increases with increasing age. In several studies, old age is considered a factor that increases the care burden (17, 18). In our study, the care burden is considered high owing to the fact that the present study was conducted among an old-old age group.

According to the results of multivariate analysis in the present study, the dependency of elderly based on the ADL and IADL indices, poor general health perception of the caregiver, and residing in the same house with the elderly were the factors increasing the burden of the caregiver.

In our study, it was observed that the dependency of the elderly as assessed by the ADL and IADL indices increases the caregiver burden. Dependence on the care of the caregiver, even for basic needs such as feeding, continence, and maintaining personal hygiene, increases the care burden. In several national and international studies, dependency is considered a factor that increases the burden (5,19-22). On the other hand, in a study conducted in Japan, it was stated there was no correlation between IADL score and caregiving burden (23). To extend the periods of independence as measured by the ADL and

IADL indices, it is anticipated that the planning and delivery of preventive healthcare services to support active aging will reduce the burden of the caregiver burden.

Residing in the same house with the elderly was identified as a factor increasing the burden of the caregiver. Most elderly individuals (70.04%) live with their caregivers in our provincial capital, a small Anatolian city where traditions are preserved. Residing with the elderly individuals increases the time spent with them. It is known that the care burden increases with the increase in the time spent with the elderly (1, 8, 14, 18). Moreover, it was observed that the level of psychological disorders, such as depression, is high among the caregivers residing with the elderly (20, 23). Increased time spent together reduces the time that caregiver can devote to rest and social interaction, thereby leading to burnout.

In our study, it was observed that the caregiver burden is high among caregivers with poor general health perception. In several studies, it has been reported that poor overall health perception of caregivers increases the level of burden (1, 5, 15). In studies conducted in Malaysia and the UK, it has been reported that the care burden increases with the worsening of the general health perception (24, 25). It was considered that the physical capacity of the caregiver could be diminished due to poor health status and care activities, particularly those requiring physical performance, further increase the caregiver burden—a caregiver with poor health condition could perceive the care provided more as a burden.

One of the limitations of the present study is with regard to explaining the casual relationship because it is a cross-sectional study. In addition, it is assumed that individuals provide honest answers to the items in the questionnaires and scales. On the other hand, the strengths of this research are that this study was, to the best of our knowledge, the first to include caregivers for the old-old individuals aged ≥ 85 years. Moreover, the study can represent Burdur province because it is a community-based study and can provide insights regarding places with similar population structure and socioeconomic characteristics.

Conclusion

The dependency of elderly based on the ADL and IADL indices, poor general health perception of the caregiver, and residing in the same house

with the elderly were the factors that increased the caregiver burden. It is anticipated that the planning of a multidisciplinary approach for raising public awareness regarding “active aging” and thus prolonging the period of independence as assessed by the ADL and IADL indices would be an effective intervention to reduce the care burden. Supporting the caregiver’s physical and mental health will improve their health perception and reduce the care burden. It is important to conduct studies in the primary care setting to improve the overall health status of the entire society and the caregivers in particular. In our

country, where the number of elderly individuals is rapidly increasing, the care burden will be reduced with applications, such as care support for the elderly and elderly nurseries that will be established within the scope of social policies, in connection to the time that caring relatives spend with the elderly. Reducing the care burden will be the most important intervention to improve the quality of care for the elderly.

Conflict of interest

There is no conflict of interest between the authors.

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