





Research Article

Ankara Med J, 2023;(4):389-399 // doi 10.5505/amj.2023.63549

CARE BURDEN AND INFLUENCING FACTORS OF ELDERLY PATIENTS RECEIVING HOME HEALTH CARE: PERSPECTIVES OF PATIENTS AND CAREGIVERS

 Ersan Gürsoy¹,  Salih Eren¹

¹Erzincan Binali Yıldırım University Faculty of Medicine, Department of Family Medicine, Erzincan

Correspondence:

Ersan Gürsoy (e-mail: ersangursoy@gmail.com)

Submitted: 20.06.2023// Accepted: 13.12.2023



Abstract

Objectives: The aim of the study was to determine the care burden and influencing factors of patients receiving home health care.

Materials and Methods: The study was cross-sectional descriptive and was conducted with patients who benefited from a tertiary hospital's home health care unit. A 25-question demographic data questionnaire was prepared by the researchers by scanning the literature, and the BARTHEL daily living activities index was applied to the patients.

Results: A total of 416 people participated in the study, 34.86% (n=145) of whom were male, and 65.14% (n=271) were female. According to the Barthel daily living activities index, 43.75% (n=182) of the patients were entirely dependent, 38.46% (n=160) were severely dependent, and their average score was 34.14 ± 29.27 . No significant relationship was found between the gender of the caregiver, closeness with the patient, education level of the patient and the perceived burden of care. On the other hand, a significant relationship was found between the education level of the caregiver, the profession, the dependency degree of the patient, and the perceived burden of care ($p=0.001$, $p=0.031$, and $p<0.001$, respectively).

Conclusion: To reduce the care burden of caregivers, it is necessary to increase the quality and accessibility of home healthcare services, provide education and support for patients and caregivers, and take measures to maintain and improve patients' independence.

Keywords: Home care services, caregiver burden, burden of illness, physical functional performance.

Introduction

Many individuals who need care for reasons such as old age, chronic illness, and injury prefer to stay in their homes and receive home health care.^{1,2} Home health care services are a service model that provides medical or supportive care to these individuals in their homes. Home healthcare services can help improve individuals' quality of life, independence, and health. In addition, home healthcare services can be more economical, more comfortable, and equally effective compared to places such as hospitals or nursing homes.³

The level of dependency on daily living activities of individuals receiving home health care services is an essential indicator for both themselves and the people who provide care for them.⁴ Daily living activities are the skills required to meet basic physical needs such as nutrition, personal care, dressing-undressing, toileting, bladder and bowel control, transfer (bed-chair), mobility on level ground, and stair climbing.⁵ A frequently used tool to measure these skills is the Barthel Index. The Barthel Index is an ordinal scale that scores each activity according to the individual's ability to perform the task independently.⁶

The level of dependency on daily living activities of individuals receiving home health care services is not only related to the physical conditions of the individuals but also to the characteristics of the people who provide care for them.⁷ Caregivers are usually relatives, friends, or acquaintances of the patients. The occupations, education levels, and closeness to the patients of the caregivers can affect the quality and quantity of the care process⁷. In addition, how the caregivers perceive their patients' care burden is also essential. Care burden can be defined as the caregiver's physical, psychological, social, and economic difficulties. As the care burden increases, the caregiver's quality of life and health can be negatively affected.⁸

This study aims to measure the level of dependency on daily living activities of patients who benefit from home health care services and to examine the factors that affect the care burden of caregivers.

Materials and Methods

Population

The study was cross-sectional and descriptive. The research was conducted with patients over 65 who received service from the Erzincan Binali Yıldırım University Hospital home health unit between 01.02.2023 and 01.04.2023.

The sample size was calculated using the G Power program. The confidence interval of the research was determined as 99%, the margin of error as 5%, and the variance as 50%. According to these values, it was found

that the sample size should be 385. Approximately 5% margin of error was also added, and the sample size was calculated as 404. In this context, interviews were conducted with 416 people.

Data collection tools

A 25-question questionnaire prepared by the researchers by scanning the literature and questioning the demographic data of the patients and caregivers, the time spent by the caregivers on care, and the chronic diseases of the patient were applied to the patients who reside in Erzincan city center and agree to participate in the study. Moreover, the 11-item BARTHEL daily living activities index, developed by Mahoney and Barthel in 1965 and modified by Shah et al. in 2000, was used to measure the level of dependency on patients' daily living activities. Küçükdeveci et al. validated the Turkish version in 2000 and applied it to the patients.⁶ The total score on the scale ranges from 0 to 100. A higher score means higher independence.

Ethics committee approval

Written and oral informed consent forms were obtained from all participants who agreed to participate in the study and from the legal guardians of the patients who could not consent. The principles of the modified version of the Helsinki Declaration were followed in every stage of the study. Approval was obtained from the Erzincan Binali Yıldırım University Clinical Research Ethics Committee with decision no 2023-02/1 for the study.

Statistical methods

The researchers entered the study data into the IBM SPSS Statistics 23 (SPSS, Chicago, IL) package program. Descriptive analyses were presented using mean \pm standard deviation (SD) for normally distributed variables, median and range (min-max) for non-normally distributed variables and the number of cases (n) and (%) for nominal variables. The normality assumption was checked using the Kolmogorov-Smirnov test. Students' t-tests and the Mann-Whitney U test were used to compare means and medians between the two groups, respectively. One-way ANOVA was employed for comparing means across more than two groups. The chi-square test was used to examine the association between categorical variables.

The level of statistical significance was taken as $p < 0.05$.

Results

A total of 416 people participated in the study. 34.86% (n=145) of the participants were male, and 65.14% (n=271) were female. The mean age was 74.75 (min=65, max=111). The other demographic data of the participants are given in Table 1.

Table 1. Demographic data of the participants

		n	%
Marital status	Married	156	37.51
	Single	47	11.29
	Widow	213	51.20
Occupation	Housewife	141	33.89
	Worker	20	4.80
	Officer	8	1.92
	Retired	131	31.5
	Not working	116	27.88
Education	illiterate	168	40.38
	Primary school	191	45.91
	Middle school	27	6.49
	High school	22	5.28
	University	8	1.92
Social security	Public insurance	272	65.38
	Special insurance	78	18.75
	None	66	15.86

The most common pathologies in the participants were the circulatory system, with 54.80% (n=228), and the nervous system, with 48.31% (n=201). The last seen pathology was visual pathology, with 1.92% (n=8).

The most frequently used services by the patients within the scope of home health care services were examination with 39.42% (n=164) and hospital transfer services with 22.83% (n=95).

The degree of kinship, marital status, and occupation of the person primarily responsible for the patient's care is given in Table 2.

The mean time spent on the patient's daily care was 11.86 ± 8.84 hours. The mean score of the patients from the Barthel daily living activities index was 34.14 ± 29.27 . According to this, 43.8% (n=182) of the patients were entirely dependent, 38.46% (n=160) were severely dependent, and 17.78% (n=74) were moderately mildly dependent or completely independent.

The caregivers' mean perceived care burden score, which was asked as 1= lowest, 10= highest, was 7.27 ± 2.3 . The relationship between perceived care burdens and various parameters is given in Table 3.

Table 2. The degree of closeness, marital status and occupation of the person primarily responsible for the care of the patient

		n	%
The primary person responsible for the care	Their children	206	49.51
	Partner	55	13.22
	Bride-groom	51	12.25
	Mom dad	25	6.00
	Caregiver	25	6.00
	Brother	13	3.12
	Other	41	9.85
Occupation of the person primarily responsible for the care	Housewife	176	42.30
	Worker	99	23.79
	Retired	58	13.94
	Officer	32	7.69
	Not working	51	12.25
The education level of the person primarily responsible for the care	Illiterate	32	7.69
	Primary school	167	40.14
	Middle school	59	14.18
	High school	95	22.83
	University	63	15.14

Table 3. Relationship between perceived care burdens and demographic data and dependency levels

		n	Perceived Care Burden (Mean±SD)	p
Gender	Male	145	7.32±2.36	0.728
	Female	271	7.24±2.34	
Education	Illiterate	168	7.43±2.35	0.403
	Primary School	191	7.09±2.42	
	Middle School	27	7.48±1.88	
	High School	22	6.91±2.22	
	University	8	8.25±1.90	
Education Level of The Caregiver	Illiterate	32	7.03±2.63	0.001
	Primary School	167	7.76±2.10	
	Middle School	59	7.56±2.23	
	High School	95	6.79±2.50	
	University	63	6.54±2.38	
Degree of Disability	Fully Dependent	182	8.07±1.94	<0.001
	Highly Dependent	160	7.22±2.11	
	Moderately Dependent	53	5.79±2.56	
	Mildly Dependent	13	4.31±2.49	
	Fully Independent	8	4.75±3.15	
Occupation of The Caregiver	Housewife	176	7.51±2.18	0.031
	Employee	99	7.39±1.91	
	Officer	32	6.25±2.39	
	Retired	58	7.33±2.57	
	Not Working	51	6.76±3.08	
The Degree of Closeness of The Caregiver	Child	206	7.17±2.33	0.111
	Partner	55	7.58±2.25	
	Bride-Groom	51	7.82±2.08	
	Mom Dad	25	7.32±2.68	
	Caregiver	25	7.76±1.87	
	Brother	13	6.62±2.66	
	Other	41	6.54±2.62	

Discussion

Home healthcare services are an increasingly demanded service area with the increase in the elderly population.⁹ Home health care services reduce hospitalizations, lower infection risk, and improve quality of life by enabling patients to receive care in home environments.⁹ However, the care burden perceived by the caregivers of these patients and the factors affecting this burden have yet to be well known. In our study, a significant relationship was found between the perceived care burden of the caregivers and the education level, occupation, and dependency level of the person responsible for care.

The mean age of the patients participating in the study was 74.75, and 65.14% of them were female. In a study conducted by Acar Tek et al. with patients receiving home care services in Ankara/Turkey, 65.1% of 407 patients were also female. The patients' mean age was 72.8 ± 6.67 .¹⁰ Although only patients over 65 were included in our study, the average age in the studies was very close to each other. Because most of the patient population is elderly, excluding patients who receive home health care because of acute problems such as bone fractures, these results also show that home health care services are preferred more by elderly and female individuals in Turkey. Among the reasons for the preference for home health care services by elderly and female individuals in Turkey, sociocultural factors, gender roles, and differences in access to health services can be mentioned¹¹. While often taking on the role of caregiver within the family, older women may have difficulty finding someone to care for themselves. In addition, older women may have lower income and education levels, limiting their access to health services.¹¹ Home health care services may be a suitable option for older women.

In our study, 54.80% of the patients had a circulatory system, and 48.31% had nervous system diseases. Similarly, in another study by Selçuk et al. in Turkey, it was observed that patients receiving home health care had the most cardiac disorders with 42.7%.¹² Among the reasons why most of the patients who benefit from home health care services have circulatory system and nervous system diseases are old age, genetic factors, lifestyle, and environmental factors. Similarly, a study conducted by Nair et al. in India found that 70% of the elderly patients receiving home health care had chronic diseases such as hypertension, 50% had diabetes, and 40% had dementia.¹³ These diseases can increase the level of dependency on the patient's daily living activities and raise the perceived care burden of the caregivers. Therefore, home healthcare services must provide medical and psychosocial support to prevent or treat these diseases. On the other hand, these findings highlight the importance of integrating chronic disease management into home health care. This may include providing caregivers with special training in managing these conditions.

The most frequently used services by patients within the scope of home health care services are examination and hospital transfer services. This finding has been similarly reported in studies conducted in other

countries.^{3,14} These services are essential for monitoring the health status of the patients, updating their treatment plans, and referring them to the hospital when necessary. Patients who cannot receive adequate examination and hospital transfer services within the scope of home health care services may experience deterioration in their health status, recurrent hospitalizations, and decreased quality of life. This highlights a critical aspect of home healthcare - the need for continuous medical monitoring and the ability to respond quickly to changes in the patient's condition.

According to the degree of closeness of the person primarily responsible for the patient's care, it was seen that the most common ones were their children, spouse, and daughter-in-law/son-in-law, respectively. On the other hand, the most common occupations of the caregivers were housewife (42.30%), worker (23.79%), and retired (13.94%). These results show, in line with similar studies conducted in Turkey, that home healthcare services are carried out within the family and that family members play an essential role.¹⁰ As expected, most caregivers are away from or have low income from working life, and most are primary school graduates. This reflects traditional family structures and caregiving norms but also raises questions about the support available to these family caregivers, who may be balancing caregiving with other personal and professional responsibilities.

The level of dependency on the patient's daily living activities was measured by the Barthel Index. The mean Barthel score of the patients was 34.14 ± 29.27 , and 43.75% were classified as entirely dependent and 38.46% as severely dependent. In a study conducted by Gdk et al. with 525 home health patients in Istanbul/Turkey, these rates were found to be 37% and 20%, respectively.¹⁵ These results show that most patients who benefit from home healthcare services are severely dependent on daily living activities. The high dependency levels observed suggest that home healthcare services are catering to a significantly impaired population, which underscores the need for comprehensive care plans that address both medical and functional needs.

Care burden can be defined as a subjective experience perceived by the caregiver as a result of providing care.¹⁶ The caregivers were asked to score between 1 and 10 to evaluate their perceived care burden. The caregivers' mean perceived care burden score was 7.27 ± 2.3 , which indicates that the caregivers feel a moderate-high level of care burden. A significant relationship was found between the perceived care burden of the caregivers and the education level, dependency level, and occupation of the person responsible for care. These results show that the caregivers feel more of a care burden as the caregiver's education level decreases, the patient's dependency level increases, and the occupation of the caregiver is housewife or worker. This finding is crucial for healthcare policymakers and practitioners, highlighting the need for interventions to reduce caregiver burden, such as respite care, caregiver training, and psychological support.

Increasing the education level of caregivers can improve both the health status and quality of life of the patient and the caregiver.¹⁷ Education programs should provide information about the nature, course, treatment, and

complications of the disease and include caregiving skills, problem-solving strategies, stress management, and coping methods. Moreover, education programs must be culturally appropriate and respectful of the beliefs and values of the caregivers.¹⁷

As the patient's dependency level increases, the caregiver has to spend more time, energy and resources. In a study conducted in Turkey that included 177 patients and caregivers, it was found that caregivers felt the burden of care the most in terms of time.¹⁸ This can lead to physical, psychological and social exhaustion. Therefore, appropriate home health services should be provided according to the patient's dependency level, and caregivers should be given respite opportunities.

The caregiver's occupation can also affect the care burden.¹⁹ Caregivers who are housewives or workers may feel more of a care burden.¹⁹ Because these occupational groups may be disadvantaged both economically and socially. Therefore, particular policies and programs should be developed for these occupational groups. For example, workers who are caregivers can be provided with opportunities such as flexible working hours, paid leave or financial support. Housewives who are caregivers can be offered services such as social security, psychosocial support or help with household chores.

Although the perceived care burden was higher in daughters-in-law and sons-in-law and lower in children, this difference was not statistically significant. Similarly, the gender of the person responsible for the care and the patient's education level did not significantly affect the care burden. These results are consistent with some studies in the literature, as well as some studies that have findings that female caregivers feel more of a care burden than male caregivers and close relatives feel more of a care burden than other relatives and non-blood relatives.²⁰ Among the reasons for these differences, it can be mentioned that the studies were conducted in different countries and cultures, different scales were used, different sample groups were selected, and different statistical analysis methods were applied. Moreover, these factors may affect the care burden not alone but in interaction with other factors. Therefore, there is a need for more comprehensive and comparative studies to understand the factors determining the care burden.

Among the limitations of this study is that it was single-centered, data based on self-reports of the patients and caregivers participating in the study were used, and the study had a cross-sectional design. Therefore, the generalizability of the results of this study is limited. On the other hand, the burden of care could not be measured with a standard scale to avoid asking too many questions and affecting the participation of patients and their relatives in the study. In future studies, it is recommended to use larger and multicenter sample groups using completely standardized scales.

In conclusion, this study showed that the dependency levels of the patients who benefit from home health services in daily living activities were high, creating a severe burden on the caregivers. Therefore, it is necessary

to increase the quality and accessibility of home health services, provide education and support for the patients and caregivers, and protect and improve the patient's independence.

Ethical Considerations: Ethical approval was acquired from the local Ethics Committee (Date: 19.01.2023, App. No: 2023-02/1).

Conflict of Interest: The authors declare no conflict of interest.

(The preliminary data of this study were presented as an oral presentation at the 12th International Trakya Family Medicine Congress in 2023.)

References

1. Landers S, Madigan E, Leff B, et al. The future of home health care: a strategic framework for optimizing value. *HHCMP*. 2016;28(4):262-78.
2. Yüce ZG, Gorpelioglu S, Emiroğlu C, Aypak C, Say YK. Nutritional status of home care patients and affecting factors throughout a six-month follow-up period. *AMJ*. 2023;23(1).
3. Boland L, Légaré F, Perez MMB, et al. Impact of home care versus alternative locations of care on elder health outcomes: an overview of systematic reviews. *BMC geriatrics*. 2017;17:1-15.
4. Pehlivanoğlu EFÖ, Özkan MU, Balcıoğlu H, Bilge U, Ünlüoğlu İ. Adjustment and reliability of Katz daily life activity measures for elderly in Turkish. *AMJ*. 2018;18(2):219-23.
5. Mlinac ME, Feng MC. Assessment of activities of daily living, self-care, and independence. *Archives of Clinical Neuropsychology*. 2016;31(6):506-16.
6. Küçükdeveci AA, Yavuzer G, Tennant A, Süldür N, Sonel B, Arasil T. Adaptation of the modified Barthel Index for use in physical medicine and rehabilitation in Turkey. *Scand J Rehabil Med*. 2000;32(2):87-92.
7. Dağdeviren T, Demir N, Adahan D, Dağdeviren M, Tekin O. Evde sağlık hizmeti alan hastaların bakım verenlerinde bakım yükü. *TJFMPC*. 2020;14(2):186-95.
8. Borges EL, Franceschini J, Costa LHD, Fernandes ALG, Jamnik S, Santoro IL. Family caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life. *JBP*. 2017;43:18-23.
9. Caner A, Cilasun SMJG. Health care services and the elderly: Utilization and satisfaction in the aftermath of the Turkish health transformation program. *GGM*. 2019;5:2333721418822868.
10. Acar Tek N, Karaçıl-Ermumcu M. Determinants of health related quality of life in home dwelling elderly population: appetite and nutritional status. *JNHA*. 2018;22:996-1002.
11. Rodgers YVDM, Zveglic Jr JE. Gender differences in access to health care among the elderly: evidence from Southeast Asia. *Asian Development Review*. 2021;38(02):59-92.
12. Selçuk KT, Avcı D. Kronik hastalığa sahip yaşlılara bakım verenlerde bakım yükü ve etkileyen etmenler. *Süleyman Demirel Üniversitesi Sağlık Bilimleri Dergisi*. 2016;7(1):1-9.
13. Nair S, Sawant N, Thippeswamy H, Desai G. Gender Issues in the Care of Elderly: A Narrative Review. *IJPM*. 2021;43(5_suppl):S48-S52.
14. Morefield B, Tomai LJHS. Distinguishing frontloading: an examination of medicare home health claims. *Health Services Outcomes Research Methodology*. 2021;21(4):477-85.
15. Güdük Ö, Güdük Ö, Sertbaş Y. Evde Sağlık Hizmetlerinden Yararlanan Hastaların Karakteristik Özellikleri ve Hizmet Talebinin İncelenmesi. *Celal Bayar Üniversitesi Sağlık Bilimleri Enstitüsü Dergisi*. 2021;8(1):78-83.

16. Scherbring M. Effect of caregiver perception of preparedness on burden in an oncology population. Paper presented at: Oncology nursing forum2002.
17. Souza ALR, Guimarães RA, de Araújo Vilela D, et al. Factors associated with the burden of family caregivers of patients with mental disorders: a cross-sectional study. *BMC psychiatry*. 2017;17(1):1-10.
18. Taşdelen P, Ateş M. Evde bakım gerektiren hastaların bakım gereksinimleri ile bakım verenlerin yükünün değerlendirilmesi. *Hemşirelikte eğitim ve araştırma dergisi*. 2012;9(3):22-9.
19. Koerin BB, Harrigan MP, Secret M. Eldercare and employed caregivers: A public/private responsibility? *Journal of Gerontological Social Work*. 2008;51(1-2):143-61.
20. Hengelaar AH, Wittenberg Y, Kwekkeboom R, Van Hartingsveldt M, Verdonk P. Intersectionality in informal care research: a scoping review. *Scandinavian Journal of Public Health*. 2023;51(1):106-24.