

# Relationship between Caregiver Health Literacy and Caregiver Burden

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**Objective:** This study was conducted in order to examine the relationship between caregiver health literacy and caregiver burden.

**Methods:** A cross-sectional and descriptive design was used. The research was carried out at the state hospital from November 2017 to January 2018. The study sample consisted of 215 caregivers. Data were collected through face-to-face interviews with a health literacy scale and a burden interview.

**Results:** The research found that the participating caregivers had a high level of health literacy and a moderate level of care burden. There was a moderately negative relationship between health literacy and caregiver burden ( $r = -.310$ ;  $p = .000$ ). It was found that as a caregiver's level of health literacy increased, that individual's burden decreased.

**Conclusion:** It is important for individuals who are caring for chronic patients and need assistance in this tough process to stay healthy in terms of decreasing the care burden. Caregivers must be adequately health literate so that they will be able to understand basic health information and develop the proper self-care behavior that will enable them to maintain and even improve their own health status. [*PR Health Sci J* 2019;38:163-169]

*Key words:* Caregiver burden, Chronic disease, Caregiver health literacy

Caregivers play an important role in providing practical, emotional, physical, spiritual, and social support to people with chronic conditions or cognitive or physical impairments (1,2). Caregivers undertake a range of activities that vary from household chores to those related to daily living and managing medications (3). For an informal caregiver, responsibilities often include encouraging the patient under his or her care to participate in self-management, support activities, such as accessing/understanding health information, communicating with healthcare providers, coordinating support services, participating in health-related decision-making and problem solving (4,5). In such instances, the health literacy of caregivers may be particularly important. Health literacy can be defined as the capacity to acquire, interpret and understand basic health information and services, which literacy enables an individual to protect, and improve his or her own health (6–8). To be considered health literate, an individual must be able to navigate the health system in place as well as effectively take control of such individual and interpersonal elements as pertain (9). People with chronic health conditions and who have low health literacy might have poor disease-management skills, suffer from reduced psychological well-being, have poor health outcomes, use health services to an inordinate degree, find themselves hospitalized for extended times, and—when the patient is elderly—have increased mortality (10–18). Lack of such literacy negatively affects caregivers as well as patients. In the literature, the effects of the level of health literacy on the patients have been investigated, but there has been a limited

number of studies performed on caregivers (2,19,20). It was thought that examining the relationship between the level of health literacy and the burdens of the caregivers who manage the chronic disease process would contribute to the literature. For this reason, the study described here in was conducted, that is, to examine the relationship between caregiver health literacy and caregiver burden.

## Materials and Methods

A cross-sectional and descriptive design was used. The study was conducted from November 2017 to January 2018 in the state hospital in Turkey. Seventeen caregivers refused to participate because of limited time (8%). The study sample consisted of 215 caregivers. The inclusion criteria for the caregivers were as follows: the caregiver was the primary person responsible for caregiving he or she provided care for at least 3 hours a day voluntarily accepted participation in the research, was literate in Turkish, had no hearing or speaking impairment,

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and was 18 years old or older. The exclusion criteria for the caregivers were having a vision, hearing, or speech impairment, having been diagnosed with any psychiatric disease, and the fact that their care was being provided to patients for a price. The questionnaire conducted by the researcher took about 10 minutes.

## Instruments

### Demographic characteristics

The first instrument consisted of 12 questions regarding the participating caregivers' socio-demographic characteristics; the questions elicited the following information: age, gender, marital status, educational status, employment status, whether or not the individual had social insurance, economic condition, whether or not the individual had a child, the individual's relationship to the patient, whether or not the individual had a chronic disease, whether or not the individual was living with the patient, and the caregiving period.

### Health literacy scale

To measure perceptions of health literacy, the Health Literacy Scale developed by Toci et al (21) and adapted for the Turkish language by Aras and Bayık Temel (22) was used. The scale consisted of a total of 25 items and 4 subdimensions. The scale was adapted to a 5 point Likert-type scale, and participants were asked to assess, on a scale ranging from 1 (unable) to 5 (able without any difficulty), their level of ability with regard to accessing, understanding, appraising, and applying health information. An overall health-literacy score was calculated for each participant, which score could range from 25 (lowest possible score) to 125 (highest possible score). In addition, 4 subscale scores (domain indexes) were calculated, taking into account the 4 domains explored, namely, accessing (range: 5–25), understanding (range: 7–35), appraising (range: 8–40), and applying (range: 5–25) health information. Higher scores correlated to higher health-literacy levels (21,22). In this study, the reliability coefficient of the scale was determined as  $\alpha = .96$ . Besides, the reliability coefficients for the subdimensions of the scale, which are access, understanding, appraisal, and application was determined higher than 0.86.

### Burden interview

To measure caregiver burden, the Burden Interview scale developed by Zarit et al (23) and adapted for the Turkish language by Özer et al (24) was used. The Zarit Burden Interview, a popular caregiver self-report measure used by many agencies on aging, originating as a 29-item caregiver self-report, the Zarit Burden Interview has been revised so that it now contains 22 items (23). The interview uses a 5-point Likert scale to record the participating caregiver's response to each item. The response options range from 0 (never) to 4 (nearly always). The standardized total score ranges from 0 to 88 (24). Higher scores reflect a greater perceived burden. In this study, the reliability coefficient of the scale was determined as 0.91.

### Ethical considerations

Written permission from the Mehmet Akif Ersoy University Ethical Committee (GO 2017/137) was obtained. The objective of the research was explained to the participants, and written permission was received from each who agreed to participate.

### Data analysis

The data were analyzed using SPSS version 22.0. Descriptive statistics were used to determine the participating caregivers' characteristics. The relationship between health literacy and caregiver burden was examined with Pearson's correlations. An  $r$  value of 0.00 to 0.24 indicated a weak relationship; 0.25 to 0.49 indicated a moderate relationship; 0.50 to 0.74 indicated a strong relationship; and 0.75 to 1.00 indicated a very strong relationship (25). For all the analyses, a  $p$  value less than 0.05 was considered significant.

## Results

### Caregivers' socio-demographics characteristics

The descriptive information regarding the caregivers in the study can be seen in Table 1. The participants were found to have a mean age of 50.15 ( $\pm 12.96$ ) years; the average caregiving period was 9.9 ( $\pm 7.0$ ) years; 66.5% were female, 86% were married, and 54.9% had graduated from high school; 52.1% were employed, 93.5% received social security, and 53.5% stated that their incomes were equal to their expenditures; 76.3% of the caregivers had a child or children living at home; and 60.9% did not have a chronic disease. Caregivers were spouses (47.4%), adult children (36.7%), or friends or other relatives (15.8%), and 72.1% of the caregivers lived with the patients to whom they were providing care (Table 1).

The mean score of the caregivers was 21.72 ( $\pm 3.64$ ) on the access subscale, 27.53 ( $\pm 6.35$ ) on the understanding subscale, 31.96 ( $\pm 7.47$ ) on the appraisal subscale, and 21.08 ( $\pm 3.92$ ) on the application subscale. The mean health-literacy score was 102.30 ( $\pm 19.67$ ) (Table 2).

The mean caregiver burden score was 27.31 ( $\pm 15.05$ ). It was found that there was a significant relationship between caregiver health literacy and the caregiver burden score averages in the access subdimension, in the negative direction and at a weak level ( $r = -.222$ ;  $p = .001$ ); in the understanding sub-dimension, in the negative direction and at a weak level ( $r = -.237$ ;  $p = .000$ ); in the appraisal subdimension, in the negative direction and at a moderate level ( $r = -.335$ ;  $p = .000$ ); and in the application subdimension, in the negative direction and at a moderate level ( $r = -.324$ ;  $p = .000$ ). It has been found that there was a significant relationship between the average health-literacy score and the average caregiver burden score, in the negative direction and at a moderate level ( $r = -.310$ ;  $p = .000$ ) (Table 2).

When the caregivers' health-literacy scores and individual characteristics were compared, a significant relationship was found to exist between caregiver age and health literacy, in the

negative direction and at a weak level ( $r = -.190$ ;  $p = .005$ ). There was a statistically significant difference between the individual characteristics of caregivers in terms of gender, educational

**Table 1.** Socio-demographic and disease-related characteristics of the participating caregivers (n = 215)

	n	%
Age ( ± SD)	50.15 ± 12.96	
Caregiving period (years)	9.9 ± 7.0	
Gender		
Female	143	66.5
Male	72	33.5
Marital status		
Married	185	86.0
Single	30	14.0
Educational level		
Illiterate	20	9.3
Primary/Secondary	77	35.8
High school/University	118	54.9
Employment status		
Employed	112	52.1
Unemployed	103	47.9
Social insurance		
Has	201	93.5
Doesn't have	14	6.5
Income status		
Income is greater than expenditures	49	22.8
Income is less than expenditures	51	23.7
Income is equal to expenditures	115	53.5
Children		
Has	164	76.3
Doesn't have	51	23.7
Chronic disease		
Has	84	39.1
Doesn't have	131	60.9
His/her relationship to patient		
Spouse	102	47.4
Adult child	79	36.7
Other (relative, friend, etc.)	34	15.8
Lives with patient		
Yes	155	72.1
No	60	27.9
Total	215	100.0

Abbreviation: SD, standard deviation.

**Table 2.** Relationship between health literacy and caregiving burden scale scores

Health-literacy scale subdimensions	Min	Max	$\bar{x} \pm SD$	Caregiving burden scale	
				$\bar{x} \pm SD$	
				27.31 ± 15.05	
				(min: 4.00, max: 74.00)	
				r	p*
Access (items 1–5)	6	25	21.72 ± 3.64	-.222	.001
Understanding (items 6–12)	9	35	27.53 ± 6.35	-.237	.000
Appraisal (items 13–20)	12	40	31.96 ± 7.47	-.335	.000
Application (items 21–25)	6	25	21.08 ± 3.92	-.324	.000
Total	37	125	102.30±19.67	-.310	.000

\* $p < 0.05$

status, social security, income status, proximity to the patient, and cohabitation status at home and average health-literacy scores ( $p < 0.05$ ). Health-literacy scores were highest among men who had high education levels, high income levels, and social insurance and care providers who did not live with the patients to whom they were providing care. In addition, there was no significant difference between marital status, employment status, and child status and having a chronic illness (Table 3).

No significant relationship between caregiver age and caregiver burden was found ( $p > 0.05$ ). There was no significant relationship between care duration (for a given caregiver) and health literacy and caregiver burden (Table 3).

Regarding the personal characteristics of the participating caregivers, there was a statistically significant difference only between social security and caregiver burden ( $p < 0.05$ ). The caregiver burden of caregivers without health insurance was higher than was the caregiver burden of those individuals with such insurance. In addition, there was no statistically significant difference between gender, marital status, education status, working status, income status, child status, chronic-illness status, caregiver's relationship to the patient, and residential status of the patient (does or does not live with the caregiver) and average caregiver burden score (Table 3).

## Discussion

To our knowledge, this is the first study to assess the relationship between caregiver health literacy and caregiver burden in Turkish caregivers of patients with chronic diseases. The caregivers who look after adults with chronic conditions or with cognitive or physical impairments play a vital role; when these individuals are not adequately health literate, the care they provide might not be sufficient to the needs of their patients, which would inevitably negatively affect the health outcomes of those patients (2,26). This makes it difficult for caregivers to manage the caregiver process (27).

According to the study results, for the participating caregivers, the prevalence of limited health literacy from 0% to 52.5%, depending on the measure. Associations were found between low health literacy in caregivers and inadequate self-management behaviors in care recipients, as well as between increased use of health services by care recipients and increased caregiver burden. The study quality ranged from fair to excellent. The percentage of caregivers determined to have low health literacy differed according to the measures and scoring criteria being used (2).

In their study, Pelle et al (2017) examined the levels of health literacy of caregivers of patients with heart failure; they determined that the majority of caregivers were female (60.1%) and aged from 46 to 60 years (52.6%). They also found that 33.5% of the caregivers who participated in their study were the patients' children, and 16.2% were paid caregivers. While the average level of health literacy in their participants was acceptable, they discovered that those caregivers who were the spouses of the patients or who were of a relatively advanced

**Table 3.** Comparing caregiver health literacy scale and caregiving burden scale mean score based on socio-demographic and disease-related characteristics (n = 215)

Age Caregiving period (years)	n	Health literacy scale	Caregiving burden scale
		X ± SD	X ± SD
		r = <b>-.190</b> p = <b>.005*</b>	r = <b>.004</b> p = <b>.950</b>
		r = <b>-.083</b> p = <b>.225</b>	r = <b>.083</b> p = <b>.224</b>
Gender			
Female	143	100.48 ± 21.03	28.52 ± 15.52
Male	72	105.91 ± 16.18	24.90 ± 13.88
		t -2.092	1.671
		p .038*	.096
Marital status			
Married	185	102.62 ± 19.98	27.00 ± 15.16
Single	30	100.33 ± 17.83	29.20 ± 14.49
		t .591	-.740
		p .555	.460
Educational level			
Illiterate	20	89.80 ± 25.91	24.75 ± 14.55
Primary/Secondary	77	104.41 ± 16.79	28.08 ± 12.68
High school/University	118	109.55 ± 19.67	27.94 ± 16.90
		KW 15.88	2.220
		p .003*	.695
Employment status			
Employed	112	106.69 ± 16.61	26.33 ± 15.27
Unemployed	103	102.48 ± 18.17	24.20 ± 14.17
		t 1.279	.732
		p .203	.465
Social insurance			
Has	201	103.03 ± 19.63	26.65 ± 14.86
Doesn't have	14	91.78 ± 17.66	36.78 ± 15.12
		U 853.000	805.500
		p .014*	.007*
Income status			
Income is greater than expenditures	49	108.26 ± 15.87	26.14 ± 15.25
Income is less than expenditures	51	102.74 ± 19.72	25.64 ± 14.68
Income is equal to expenditures	115	99.57 ± 20.66	28.54 ± 15.15
		F 3.44	.846
		p .034*	.431
Children			
Has	164	101.73 ± 19.91	27.28 ± 15.29
Doesn't have	51	104.13 ± 18.93	27.39 ± 14.40
		t -.760	-.044
		p .448	.965
Chronic disease			
Has	84	101.82 ± 20.52	25.67 ± 15.61
Doesn't have	131	102.61 ± 19.18	28.35 ± 14.64
		t -.289	-1.275
		p .773	.204
His/her relationship to patient			
Spouse	102	99.26 ± 21.28	26.55 ± 14.65
Adult child	79	106.70 ± 16.96	27.53 ± 15.77
Other (relative, friend, etc.)	34	101.20 ± 19.16	29.05 ± 14.81
		F 3.321	.363
		p .038*	.696
Lives with patient			
Yes	155	100.05 ± 20.89	27.28 ± 14.14
No	60	108.13 ± 14.70	27.38 ± 17.31
		t -2.743	-.043
		p .002*	.968

\*p<0.05

age had relatively lower health-literacy levels (19). This result is parallel to that of our study: As the educational status of our participating caregivers increased, the level of health literacy also increased. In our study, the caregivers had a mean age of 50.15 (±12.96) years, the average caregiving period was 8.9 (±5.7) years, the majority (66.5%) of the caregivers were female, and the caregivers tended to be either spouses (47.4%) or adult children (36.7%). As was the case in the study of Pelle et al, we found the average level of health literacy in our caregivers to be adequate (19). When the general health-literacy averages of caregivers are taken into consideration, it has been found that the average level increases linearly as education level increases (27). Our results showed that caregivers have an adequate level of health literacy, in contrast to what was found in other studies (28,29). In our study, it was found that as age increased, the average health-literacy score decreased. When the caregivers' health-literacy scores and individual characteristics were compared, it was found that there was a significant relationship between each caregiver's age and his or her health literacy, in a negative direction and at a weak level (r = -.190; p = .005). The reason for this is the decline in the level of health literacy in elderly individuals; it is thought that there may be effects on the natural process brought on by aging, changes in the level of interest, interaction with environmental stimulus, inefficiency in perception, lack of attention, and functional decline.

Having the potential to increase the strain and stress experienced by caregivers (2), the lack of sufficient health literacy has been associated with increased (caregiver) distress (30), burden (31), and overall dissatisfaction with the health care system (32). In our study, the caregiver burden was found to be below average. In a study by Mollaoğlu et al, which dealt with, among other things, the care burden and the factors affecting it in the caregivers of stroke patients, the caregiver burden scale score of the caregivers was found to be moderate (33). Compared with what can be seen in our study results, the care burden of stroke-patient caregivers was higher. As to the reason for this, in our study, there was no chronic illness selection, all chronic illnesses were included in the sampling. In this study, the burden of special care for patients with chronic illnesses was not evaluated. In the study, it was found that male caregivers had a higher scale score when socio-demographic characteristics and the caregiver burden scale scores of the caregivers were compared; in addition, the burden of a given caregiver increased as his or her age increased, but the difference was not statistically significant. In the study, the care burden scores of illiterate caregivers and caregivers with health problem were significantly higher. In addition, as the duration of care increased, the burden of the caregivers was found to increase (33). In our study, the level of health literacy was higher in married caregivers, working caregivers, and those without chronic disease, but the difference was found to be statistically insignificant. In addition, the level of health literacy of male caregivers was higher, and the average level of health literacy was found to increase as education level increased. Moreover, those who had social security and good

income status had higher health literacy average scores; the difference was statistically significant.

Selçuk and Avcı (34) studied care burden and the factors affecting it with caregivers serving elders with chronic illnesses; the average score of the Zarit Caregiver Burden scale was found to be higher in caregivers who undertook the care of elders in the age group of 85 years and older; caregivers with lower education levels, no health insurance, who were married, and were second-degree relatives of the elder under care; and caregivers who had taken care of an elderly patient for 37 months or longer ( $p < 0.05$ ). The care burden of the caregivers that participated in our study was found to be lower than that of the caregiving participants in the study of Selçuk and Avcı; in their study, the average score of the caregivers was higher than it was in our study. We believe the reason for this to be that the Selçuk and Avcı study was conducted with caregivers who took primary responsibility of and provided primary care to individuals in the 65 years old and older age group with at least 1 chronic illness. In our study, caregiver age was not used as a criterion for inclusion. The average age of the caregivers in our study was 50.15 ( $\pm 12.96$ ) years. This result indicates that the average age of caregivers in our study was lower than that of caregivers who participated in the Selçuk and Avcı study. In parallel with the study, it was found that the care burden of caregivers without social security was higher, and the difference was statistically significant (34). On the other hand, contrary to those study results, we found that those with low education levels had a low care burden, but the difference was not statistically significant. It is stated in the literature that one of the factors affecting care burden is the education level of the caregiver and that the caregiver's level of care burden increases as the education level of the caregiver decreases (35,36); some studies, however, have found that education level does not affect care burden (37). In our study, the fact that the level of education did not affect care burden may be because the vast majority of the caregivers who participated had a high school or above education. The variable that most affected care burden in our research was health insurance: The care burden was higher in caregivers without health insurance. This finding is compatible with the results of other, similar, studies in the literature (38,39). This can be explained by the economic burden levied by the treatment of chronic illness as well as the greater economic difficulty of meeting the care needs of elderly caregivers who do not have health insurance. In Turkish society, the care of the elderly is determined by traditional values, and often the preferred caregivers are first-degree relatives, such as a spouse or a child. In this research, it was found that the caregiving burdens of the family members (wife and adult child) who gave care to closely related patients were lower than were the burdens of those who were less closely related, such as more-distant relatives and friends, but the difference was not statistically significant. In the Turkish culture, family caring for family is accepted as the norm; the person who takes care of an elderly family member perceives it as his or her duty. In addition, 66.5% of the primary caregivers in this study

were women, and the care burden of the women was higher than that of the men, but the difference was not statistically significant. The fact that the majority of caregivers are women can be interpreted as a result of the perception that giving care is the main responsibility of women in the traditional structure of our society. In some studies described in the literature, it has been put forth that the variables of age, gender, income status, employment status, and care duration affect the care burden (35,36,40,41); however, in others, it has been reported that these variables do not affect the care burden (37,42,43). It was also found that the variables mentioned in this study did not affect the care burden when that of social security was excluded, and the difference was not statistically significant.

When the literature was examined, it was found, in general, that there was no difference between the genders in terms of care burden (44); nevertheless, many studies have found that the care burden of women caregivers is higher (45–47). It is thought that women may feel more of the burden of care given their social roles, such as being a spouse and a mother. When the educational status and burden scores of the individuals giving care in the study were examined, it was found that there was no significant difference. In our study, the results obtained were in support of those in the literature.

## Conclusion

Care burden must be considered when evaluating individuals who are caring for patients. It is necessary to identify the factors affecting the care burden, to identify the needs of the caregiver and his or her own health concerns and available support resources, and to plan initiatives for reducing the care burden of caregivers, in both institutional and home environments. It is thought that the study will contribute to the literature, as the relationship between the level of health literacy and the burden of caregivers currently remains unclear. The limitation of the study is that the number of samples is inadequate. In the future, qualitative studies should be conducted in order to find out how health literacy affects caregiver burden.

## Resumen

Objetivo: El propósito de esta investigación es estudiar la relación entre la alfabetización en salud de los cuidadores y la carga de los cuidadores. Métodos: Se utilizó el diseño transversal y descriptivo. La investigación se llevó a cabo en el hospital estatal de noviembre 2017 a enero 2018. La muestra del estudio consistió en 215 cuidadores. Los datos se recopilaron a través de entrevistas cara a cara con la escala de alfabetización en salud y entrevista de carga. Resultados: La investigación encontró que los cuidadores tenían un nivel más alto de educación en salud, así como un nivel moderado de carga de atención. Hubo una relación moderadamente negativa entre el conocimiento de la salud y la carga del cuidador ( $r = -.310$ ,  $p = .000$ ). A medida que aumenta el nivel de alfabetización en

salud de los cuidadores, se encuentra que la carga del cuidador disminuye. Conclusión: Es importante para las personas que cuidan a pacientes crónicos y necesitan asistencia en este difícil proceso mantener la salud en términos de disminuir la carga de la atención, comprender e interpretar información básica de salud para mantenerse saludable y mejorarla, para capacitar a desarrollar comportamientos adecuados a esto, aumentando así la alfabetización en salud.

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