Effects of care burden on the life of caregivers of the elderly
A mixed-method study model

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Abstract
Determining the care burden of elderly caregivers in the early period allows for early intervention to protect them from the negative physical, social, and psychological effects of care. This mixed-method study aimed to determine the burden levels of caregivers of elderly individuals and evaluate their opinions on the difficulties they experienced while caregiving. This study was conducted with caregivers of 89 elderly people who were determined to need care by visiting the homes of elderly people aged 65 years and over living in Famagusta. While the KATZ index of independence in activities of daily living and the Zarit Burden Interview tool were used to collect quantitative data, face-to-face interviews were conducted with 28 selected participants to collect qualitative data. The mean age of the caregivers was 52 ± 12 years; they were mostly female spouses/children/relatives, and 29.2% had moderate-to-severe care burden perceptions. The perception of caregiver burden levels increased as the level of dependency of elderly individuals and the duration of caregiving increased. Considering that caregiving burden affects every aspect of caregivers’ lives, it should be assessed regularly. To reduce care burden, it is recommended to expand home care services and short-term care facilities, use health technologies for continuous distance education and counseling in elderly care, and financially support caregivers who cannot work due to the responsibilities of providing elderly care.

Abbreviations: KATZ-ADL index = KATZ index of independence in activities of daily living, TRNC = Turkish Republic of Northern Cyprus, ZBI = Zarit Burden Interview.

Keywords: care, care burden, elderly, nursing
2. Methods
This study was conducted using a mixed method design. The study was conducted in the Famagusta region of the TRNC from February 2016 to December 2017. Including 89 caregivers, all of whom met the following inclusion criteria: voluntarily agree to participate in the study, be 18 years of age or over, speak Turkish, have no communication-related problems, be the primary caretaker of the elderly person under their care, and be the primary caretaker of the elderly person under their care for at least 6 months. Those who refused to participate and those who were not at home during home visits were excluded from the study.

In this study, the descriptive features form created in line with the literature, the Zarit Burden Interview (ZBI), and the KATZ index of independence in activities of daily living (KATZ-ADL index) were used. Data were collected via face-to-face interviews conducted at the homes of elderly individuals. Each interview took approximately 30 to 45 minutes to complete. In the first stage of the study, sociodemographic characteristics and data related to the KATZ-ADL index were obtained from the elderly and their caregivers. In the second stage, the ZBI was filled out by the caregivers in a separate room. A questionnaire was administered to 28 female caregivers who agreed to answer the open-ended questions.

2.1. Data analysis
Data were inputted into BM SPSS Statistics, Version 20.0 (IBM Corp., Armonk, NY) and analyzed using descriptive tests. The t test, one-way ANOVA, Mann–Whitney U test, and Kruskal–Wallis test were used to compare the sociodemographic data against the scale scores. Linear regression analysis was used to assess the effects of the variables on caregiving burden, and Pearson’s correlation analysis was applied to assess the relationship between the scores on the two scales. The threshold for statistical significance was set at \( P < .05 \).

Raw qualitative data were created by the researcher participating in the interviews via the transfer of the participants’ responses to a Microsoft Word document. Two other researchers have read the transcripts several times. Content analysis was performed by considering the frequency of repeated words used by the participants, any comments they added to their responses, the number of participants making the same comment or using the same word, and the originality of the subjects they addressed the comments they made.

2.2. Ethical dimension
Before the study, ethics committee approval was obtained from the University of Research and Publication Ethics Board (2016/28-05). Written informed consent was obtained from the caregivers who agreed to participate in the study.

3. Results
The sociodemographic characteristics of the caregivers and elderly individuals are shown in Table 1. It was found that 42.7% of caregivers had mild levels of perceived burden. Table 2 shows that the caregiving participants who had a chronic renal failure \( (P = .023) \) and were providing care to a dependent elderly person \( (P = .001) \) had higher scores on the ZBI. The participants who did not receive a formal education \( (P = .029) \), had income equal to expenses \( (P = .043) \), had been providing care for more than 5 years \( (P = .001) \), were the spouse of the elderly \( (P = .004) \), had articular and rheumatic diseases \( (P = .005) \), and asked for support with elderly care from their relatives \( (P = .001) \) or an institution \( (P = .002) \) also had higher scores on the ZBI. The participants expressed that they could not spare time for themselves (33.7%), that elderly person asks for more care than they need (14.6%), that caregiving harms their health (31.5%), that they experience difficulties managing their responsibilities related to their family, friends, and work (27.0%), that their social life is negatively affected (28%), and that they have financial problems (22.5%) had higher levels of perceived caregiver burden \( (P = .001) \).

A strong negative linear correlation was found between the scores on the KATZ-ADL index and those on the ZBI \( (r = -0.831, P = .001) \), meaning that the caregivers’ scores on the ZBI decreased as the dependency levels of the elderly increased (Table 3). Table 3 shows that the dependency of the elderly person, the duration of caregiving, and the education level of the caregiver explained 72.9% \( (P = .001) \) of the variance in caregiver burden. The levels of perceived caregiver burden increased as dependency on the elderly person \( (R^2 = 69\%; P = .001) \) and the duration of caregiving \( (R^2 = 48\%; P = .001) \) increased, while the perceived caregiver burden decreased as the education levels of the caregivers increased \( (R^2 = 0.73\%; P = .010) \).

**Table 1**

| Sociodemographic characteristics of the caregivers and elderly individuals. |
|-----------------------------|----------------|----------------|
| Variables | Number | % |
| Elderly | | |
| Age, mean: 81 ± 7.78 | | |
| 65–74 | 20 | 22.5 |
| 75–84 | 36 | 40.4 |
| 85 and more | 33 | 37.1 |
| Chronic diseases, mean: 2.80 ± 2.31 | | |
| Yes | 82 | 92.1 |
| No | 7 | 7.9 |
| Chronic diseases* | | |
| Hypertension | 54 | 60.7 |
| Diabetes | 41 | 46.1 |
| Heart failure | 33 | 37.1 |
| Caregiver | | |
| Age, mean: 52 ± 12 yr | | |
| 24–44 | 20 | 22.5 |
| 45–64 | 56 | 62.9 |
| 65 or higher | 13 | 14.6 |
| Gender | | |
| Female | 85 | 95.5 |
| Male | 4 | 4.5 |
| Marital status | | |
| Single | 24 | 27.0 |
| Married | 65 | 73.0 |
| Place of residence | | |
| At home with their spouse | 50 | 56.2 |
| At home with their elderly relative | 29 | 32.6 |
| With their children | 10 | 11.2 |
| Employment status | | |
| Employed | 44 | 47.7 |
| Retired | 18 | 22.5 |
| Housewife | 27 | 31.8 |
| Chronic diseases | | |
| Yes | 40 | 44.9 |
| No | 49 | 55.1 |
| Chronic diseases* | | |
| Hypertension | 27 | 30.3 |
| Diabetes | 20 | 22.5 |
| Heart disease | 12 | 13.5 |
| Articular and rheumatic diseases | 12 | 13.5 |
| Caregiver burden | | |
| 0–20 no | 25 | 28.1 |
| 21–40 mild | 38 | 42.0 |
| 41–60 moderate | 24 | 27.0 |
| 61–88 severe | 2 | 2.2 |
| Mean = 31.49 ± 15.49, total | 89 | 100 |

*Multiple selections were made.
Table 4 shows some of the caregivers’ answers to questions about their experiences in the caregiving process.

4. Discussion

Turkish culture has a negative view of placing elderly people in nursing homes. Therefore, most female family members undertake caregiving responsibilities. Females who take on the role of caregivers express respect, love, and gratitude to their elderly relatives who raised them in this way.\[9,10\] Timur et al and Unver\[10,11\] found in their study that caregivers of the elderly were mostly female spouses and daughters. Similarly, nearly all caregivers in this study were female (95.5%) spouses and daughters of the elderly.

Participants in our study had mild levels of perceived caregiver burden. The ZBI scores of caregivers increased with increasing dependency on elderly individuals ($P = .001$). Studies in the literature support this finding.\[1,10\] Previous studies have shown that an increase in the age and duration of caregiving, as well as a decrease in education level, degree of closeness with the elderly, decrease in income, the emergence of chronic diseases, and the...
inability to receive professional support, increase the caregiver burden of caregivers.\(^{19,12}\) Similarly, this study found that the caregivers who had lower levels of education and income, articular and rheumatic diseases, and who had been providing care for more than 5 years had higher levels of perceived caregiver burden (\(P < .05\)), whereas the caregivers who were paid caregivers had mild levels of perceived caregiver burden (\(P = .004\)). In face-to-face interviews with female informal caregivers, they

### Table 3
The variance among the dependency level of the elderly, duration of caregiving, and education level and burden of the caregiver.

| Factors                                      | \(r\) | \(R^2\) | \(F\) | \(P\) | beta | \(t\) | \(P\) | Adjusted \(r^2\) | F change |
|----------------------------------------------|-------|---------|-------|-------|------|-------|-------|------------------|----------|
| KATZ ADL index score duration of caregiving  | 0.739 | 0.548   | 0.001 | 0.001 | 24.453 | 0.001 | 0.729 | 80.074           | 80.074   |
| KATZ ADL index score                         | 0.693 | 0.480   | 0.001 | 0.001 | 6.944  | 0.001 | 0.659 | 0.000            |          |
| Duration of caregiving                        | -0.270| 0.073   | 0.010 | 0.084 | -2.620 | 0.010 | 0.406 |                  |          |

\(R^2 = \) Education Level of the Caregiver, KATZ-ADL index = KATZ index of independence in activities of daily living.

### Table 4
The caregivers’ responses to the questions on their experiences during the caregiving process.

| Theme/subtheme                                      | Participant (P24): Even turning my father over in bed and sitting him down is a big deal. What’s more, I have intense lower-back pain from time to time; I cannot walk. There is no one to help me out. (P12): It is not easy to satisfy the elderly and meet their needs. I sometimes feel suffocated. I have had migraines for 2 yr. When it attacks, it last 2 d. (P4): I am providing care to my uncle. I am 76 years old, and he is 85 years old. He is not bedridden. The kids do the shopping, but even doing the household chores is too much for me. He keeps the television on all day and turns the volume way up because he cannot hear, but it drives me crazy! I get angry, my blood pressure goes up. I have been providing care to him for 8 yr. Now I need someone to provide care for me. (P16): I am not young either. I am taking care of two houses. My mother can barely move, and it is not easy to lift her out of the bed and lay her back down in the bed again. Thank God my father can look after himself. He also helps my mother. My back and legs ache, I cannot eat regularly, and my stomach also aches. I cannot even go to the doctor. (P7): It takes up the entire day to take her to and from the hospital. We are living in the same house. She is watching my every movement. When I get dressed, she asks where I am going. It is like I, my husband, and my kids do not need anything. She gets sick when I plan to go out or when someone is going to visit us. I cannot make time for myself at all. It is really difficult to care for an elderly person. |
|-----------------------------------------------|----------------------------------|
| Need for support/increased duration of caregiving, insufficient support with caregiving, Financial problems | (P3): Everything is too expensive. We have to buy both my mother’s and my father’s drugs. My father has a low salary. When we buy the drugs without prescriptions, we pay too much. We bought a saccharometer for my mother, but its sticks are expensive, and we cannot afford it. I know it is necessary for her health, but what can I do? (P7): I have four siblings, and all of them are working. I am the only one who is not employed, so I took my mother into my home to look after her. But I get tired. I want to go away sometimes, but my siblings do not care. They think that I am the best suited to watch her since I am not employed. I just want to spend time with my family at least 1 or 2 mo out of the year. (P11): My mother has Alzheimer’s disease. I have been providing care to her for 11 yr. She has not been able to move by herself for 2 yr. Do you think it is easy? I am taking care of her willingly, but every day is the same, and every year is worse than the previous one. I sometimes get angry and upset about something minor. I was not like that in the past. I want to get away from it all, even for a short time, but there is no one to whom I can leave the task of caretaking for my mother. (P27): My mother has been bedridden for 2 yr. Diapers are too expensive. We cannot afford it. We are trying to look after her with the salary from my father. We cannot make time for myself. She asks why we are not taking her to the hospital and also for her drugs. |
| Invisibility/Damaged sense of justice, Unappreciated efforts for caregiving, Feeling of Comfort/Discomfort | (P3): I visit my mother before going to my own home. I want her to stay with us, but neither she nor my husband wants this to happen. My mother says I took care of you, but you do not want to take care of me. I can’t keep up with the tasks. I became bad-tempered when I cannot meet my responsibilities. No one understands me. I have a bad feeling all the time. (P5): My husband says: “Share the caregiving responsibilities with your sister.” But my sister has a child with disabilities. I feel sorry for her. No one notices that I am rushing around and that I am tired. They also do not want to hear it. This is not fair. (P9): Everyone does what they want to do. My brother and his wife do not care at all. If you are complaining about it, you are the bad guy. If you do not talk about it, you are resigned to brooding. Since my mother is not bedridden, they think that I do not do anything. No one sees what I am doing. (P25): It has been 6 or 7 yr since I went on a carefree holiday. I think about leaving my parents to my brother and letting him take care of them. But I fear that he will always be asking me questions about everything related to caring for them. When I go somewhere, my mind is always at home. My body rests, but my heart is always restless. |

\(R^2 = \) Education Level of the Caregiver, KATZ-ADL index = KATZ index of independence in activities of daily living, \(R^2 = \) linear regression analysis.
stated that they experienced physical, psychological, and social difficulties due to the extended duration of caregiving and that they needed both financial and emotional support for the care of the elderly. The number of elderly care centers in the TRNC where the study was conducted is insufficient, and there are no elderly care organizations to educate or support caregivers. It is believed that caregivers who do not receive adequate support experience a greater caregiver burden.

The presence of chronic diseases in elderly individuals is a factor that increases caregiver burden. A study conducted in Italy found that caregivers who did not receive support from their family members or social environment during the caregiving process had higher levels of caregiver burden. Similarly, this study found that 92.1% of the elderly and 44.9% of caregivers had chronic diseases. In addition, the caregivers expressed that their social life was negatively affected, that they could not make time for themselves, that they experienced difficulties managing the responsibilities for their family, friends, and work, that they needed support from their relatives, or that they had higher levels of perceived caregiver burden ($P < .05$).

The main limitation of this study is that it can only be generalized to caregivers of elderly individuals in the Famagusta region.

5. Conclusion

For the care process to be carried out correctly and efficiently, it is very important to have home care services that will support caregivers and monitor the needs of the elderly. Furthermore, it is critically important that health and social state policies related to elderly care be reorganized. In this regard, it is recommended to create elderly care hotlines, develop videos and visual training materials, plan activities aimed at increasing the motivation of caregivers, and establish short-term care centers.

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References

[1] Aung TNN, Aung MN, Moolphte S, et al. Caregiver burden and associated factors for the respite care needs among the family caregivers of community-dwelling senior citizens in Chiang Mai, Northern Thailand. Int J Environ Res Public Health. 2021;18:5873.

[2] Sağlam Z, Koç Z, Çınarlı T, et al. Determination of factors affecting care giving load and affecting factors of people providing care to individuals aged 65 and higher [in Turkish]. J Med Sci Samsun. 2016;1;40–60.

[3] Korkmaz B, Firat Kilıç H. Burden of family caregivers of the elderly and factors affecting their burden. Turkish J Geriatrics. 2019;22:474–81.

[4] Şelçuk KT, Avşar D. The care burden of caregivers caring for elderly with chronic diseases and affecting factors [in Turkish]. SDU Sağlık Bilim Derg. 2016;7:1–9.

[5] Association of elderly rights & mental health and British residents society joint press release. Elderly rights and mental health association. [Internet]. Available at: https://yashihaklariveruhsagligi.org/ [access date January 21, 2022].

[6] Rajabi-Mashhadi MT, Mashhadinejad H, Ebrahimzadeh M, et al. The Zarit Carer Burden Interview Short Form (ZBI-12) in spouses of veterans with chronic spinal cord injury, validity and reliability of the Persian version. Arch Bone J Surg. 2015;5:56–63.

[7] Adelman RD, Tmanova LL, Delgado D, et al. Caregiver burden: a clinical review. JAMA. 2014;311:1052–9.

[8] Bekdemir A, İllhan N. Predictors of caregiver burden in caregivers of bedridden patients. J Nurs Res. 2019;27:1–9.

[9] Gök Metin Z, Karadas C, Balci C, et al. The perceived caregiver burden among Turkish family caregivers providing care for frail older adults. J Transcult Nurs. 2019;30:222–30.

[10] Unver V, Başak T, Tosun N, et al. Care burden and self-efficacy levels of family caregivers of elderly people in Turkey. Holist Nurs Pract. 2016;30:166–73.

[11] Kayaaşp A, Page KJ, Rospenda KM. Caregiver burden, work-family conflict, family-work conflict, and mental health of caregivers: a mediational longitudinal study. Work Stress. 2021;35:217–40.

[12] Farohni JO. Correlate of burden and coping ability of caregivers of older adults with chronic illness in Nigeria. Scand J Caring Sci. 2018;32:1288–96.

[13] Farohni JO, Olaogun AA. The influence of caregivers’ burden on the quality of life for caregivers of older adults with chronic illness in Nigeria. Int Psychogeriatr. 2017;29:1085–93.

[14] Akyl GT, Erdoğan Z, Oxdenir B, et al. Quality of life of caregivers of chronic kidney failure patients [in Turkish]. Nephrology Nursing J. 2018;2:91–7.

[15] Raggi A, Tasca D, Panerai S, Neri W, Ferri R. The burden of distress and related coping processes in family caregivers of patients with Alzheimer’s disease living in the community. J Neurol Sci. 2015;358:77–81.

[16] Dansy J. Carer narratives of fatigue and endurance in Japan and England. Subjectivity. 2017;10:411–26.

[17] Ek A, Na S. The burdens on caregivers of patients above 65 years old receiving hemodialysis: a qualitative study [in Turkish]. Heal Care Curr Rev. 2014;2:1–6.

[18] Mashayekhi F, Pilevarzadeh M, Rafati F. The assessment of caregiver burden in caregivers of hemodialysis patients. Mater Socio Medica. 2015;27:333.