ASSESSMENT OF SLEEP, PROFILE OF MOOD STATES AND CAREGIVER BURDEN IN CAREGIVERS OF HOME CARE PATIENTS*

İlknur Can[1] , **Hasibe Tekşan[2]** , **Ayşe İzgi[2]**

1. Medipol University Esenler Health App. and Rese. Hospital physical med. and rehabilitation clinic, İstanbul

2. T.C Ministry of Health Şemdinli State Hospital, Psychosocial Support Unit, Hakkâri

ABSTRACT

This study was carried out to compare sleep quality and profiles of mood states of caregivers with those of people in a control group who were in the same age range and did not provide care. It was also aimed to evaluate caregiver burden. The study included 122 volunteer caregivers aged 18–45 who were giving care to people needing home care and 60 volunteer non-caregivers. The Profile of Mood States (POMS) test and the Pittsburgh Sleep Quality Index (PSQI) were administered to assess mood and sleep quality, respectively, and to compare the groups. In addition, the Zarit Caregiver Burden Scale and the Caregiver Self-Assessment Questionnaire (CSAQ) were administered. Statistical significance was set at p < 0.05 level, and results were expressed in the form of mean ± standard deviation. Mean caregiver burden score was 34.5 ± 10.4. Among the 122 caregivers, caregiving burden was high in 0.8%, moderate in 26.2%, and mild in 68%. Mean CSAQ score was 5.1 ± 2.6. A total of 54.9% of the caregivers were found to suffer caregiving burden according to CSAQ. The total PSQI and POMS scores were not significantly different between the groups. Caregiver burden correlated positively with total POMS scores, tension-anxiety, depression, anger-hostility, fatigue and confusion. Moreover, PSQI scores correlated positively with caregiver burden, total POMS scores, tension-anxiety, depression, anger-hostility, fatigue and confusion. The sleep quality and profiles of mood states of the caregivers were similar to those of the people in the control group.

Keywords: Home care, Caregiver burden, Mood states, Sleep quality

EVDE BAKIM HASTALARININ BAKIM VERENLERİNDE UYKU, DUYGU DURUM PROFİLİ VE BAKIM VEREN YÜKÜNÜN DEĞERLENDİRİLMESİ

ÖZET

Bu çalışmada evde bakım ihtiyacı olan hastaların bakım verenlerinde uyku ve duygu durumu profili aynı yaş grubundaki bakım vermeyen kontrollerle karşılaştırıldı. Aynı zamanda bakım verenlerin yükününün değerlendirilmesi amaçlandı. 18-45 yaş aralığında evde bakım ihtiyacı olan bireylere bakım veren 122 gönüllü ve benzer demografik özelliklere sahip bakım vermeyen 50 gönüllüye duygu durumunu değerlendirmek için Duygu Durum Profili ve uyku kalitesini değerlendirmek için Pittsburgh Uyku Kalitesi Endeksi (PUKİ) testleri uygulanarak elde edilen veriler gruplar arasında karşılaştırıldı. Bunun yanında bakım veren gönüllülere bakım verme yükü anketi (Zarit) ve bakıcı öz değerlendirme anketi uygulanarak sonuçlar değerlendirildi. İstatistiksel anlamlılık p<0,05 olarak alındı ve sonuçlar ortalama ve standart sapma ile ifade edildi. Bakım veren yükü ölçeği ortalama skoru 34,5±10,4 olup 122 bakım verenin; %0,8 inde yüksek, % 26,2 orta, %68' i hafif düzeyde bakım yükü tespit edildi. Bakıcı öz değerlendirme anketi skoru 5,1±2,6 olarak bulundu. Bakım verenlerin %54.9' unda bakıcı öz değerlendirme anketine göre bakım veren yükü tespit edildi. Duygu durum profili ve PUKİ skorlarında gruplar arasında anlamlı fark yoktu. Korelasyon analizinde PUKİ ile bakım veren yükü, duygu durum profili total skoru, gerginlik-anksiyete, depresyon, öfke-saldırganlık, yorgunluk, konfüzyon, arasında pozitif yönde anlamlı korelasyon vardı (p<0,05). Bakım veren yükü ile gerginlik-anksiyete, depresyon, öfke-saldırganlık, yorgunluk, konfüzyon arasında pozitif yönde anlamlı korelasyon vardı (p<0,05). Bakım verenlerin uyku kalitesi ve duygu durum profili kontrol grubuyla benzer bulundu. Bununla beraber, bakım veren yükünün artması ile uyku ve duygu durum profili skorlarının da arttığı tespit edildi.

Anahtar Kelimeler: Evde bakım, Bakım verme yükü, Duygu durumu, Uyku kalitesi

INTRODUCTION

The rate of elderly population is increasing rapidly in our country, Turkey, as in the world. According to the Turkish Statistical Institute, there were 5 million 891 thousand 694 elderly people (aged 65 and over) in our country in 2013; the number increased by 17% in the last five years, and in 2017 there were 6 million 895 thousand 385 elderly people (1). Due to the increase in the elderly population, the old-age dependency ratio has also increased. This rate increased from 6.5% in 1940 to 8.2% in 1970 (2). Accordingly, diseases that are common in old age are becoming a serious issue in the community. However, it can be said that almost all health care systems are insufficient to provide comprehensive health care services (3,4). Treatment practices, and economic and political approaches have led to a system where chronic patients are given care by their families and relatives (3,4).

Caregiving is defined as a person's dedication to the care of another individual who is unable to perform activities of daily living due to a physical or mental disorder (5). It is a very difficult task for both the caregiver and the patient. Caregiving burden can be defined as feelings of pressure, difficulty and bearing a load felt by a person who cares for someone with chronic illness and accompanying disability (6). Caregivers may experience physical, psychological, social and economic impact during caregiving (7). Research has shown that caregiver burden

after a long-term caregiving process can lead to serious consequences such as depression, anxiety, deteriorating physical health, social isolation, burnout and so forth (8,9). In addition, factors such as the fact that caregivers often take care of a person of their own family, that there is emotional burden experienced by the patient and the caregiver, that caregivers themselves may have health problems, that caregivers receive little adequate social support, and that caregivers have limited social activity can lead to depression and anxiety in caregivers (8,9). Depression and anxiety are serious problems that affect caregivers' quality of life directly and patient care indirectly (10,11).

There are not many studies on caregivers in Turkey. Caregivers have to cope with problems of their patients at home alone. Determining the problems that caregivers experience can be considered to improve the quality of life of both patients and caregivers. It can also contribute to the development of home care measures and practices. In this study, it was aimed to compare the changes in sleep and profiles of mood states of caregivers of home care patients with the changes in those of people in the same age group. We also aimed to evaluate caregiver burden experienced by the caregivers.

MATERIALS AND METHODS

This study was conducted between January and March 2019 at the Home Care Service unit of Hakkari Şemdinli State Hospital after the necessary permissions were obtained. The conduct of this study was approved by the Medical and Health Sciences Research Board and Ethics Committee of Van Education and Research Hospital (No: 01-2019, Date: January 03, 2019). A total of 122 volunteers (Group 1) aged between 18 and 45 years who cared for individuals in need of home care, had no physical or mental disability nor any psychiatric or neurological diseases were included in the study, in addition to 60 volunteer people with similar demographic characteristics in the control group (Group 2). Demographic data of all participants were recorded. The caregivers' affinity with the patient, duration of care, and areas of difficulty they experienced when giving care were questioned. The Caregiver Self-Assessment Questionnaire, the Profile of Mood States (POMS), the Pittsburgh Sleep Quality Index (PSQI), and the Zarit Caregiver Burden Scale (ZCBS) — which measures the effect of the chronic disease on family and the family's ability to cope with the disease — were administered to the caregivers. POMS

and PSQI tests were administered to the control group as well. Finally, the results were compared.

Data Collection Instruments

Zarit Caregiver Burden Scale (ZCBS)

The scale was developed by Zarit et al. (7). The validity and reliability study of the scale in Turkish was carried out by Özlü et al. (12). One can score a minimum of 22 points and a maximum of 110 points on the scale. The scores between 22 and 46 indicate mild burden, those between 47 and 55 indicate moderate burden, and those equal to or greater than 56 indicate severe burden. The scale items are generally oriented towards the social and emotional areas, and high scores on the scale indicate that the caregiver burden is high (10,12).

Caregivers Self-Assessment Questionnaire (CSAQ)

The scale was developed by the American Medical Association for the Health in Aging Foundation (13). The validity and reliability study of the scale in Turkish was conducted by Aşkın et al. (14). The scale consists of 16 items grouped in a factor that includes positive and negative dimensions of caregiver responses. It also has two specific items for stress and health levels. The scale evaluates caregivers' emotional and physical distress, depression, burden and grief. High scores on the scale indicate a high level of stress resulting from care activities.

Profile of Mood States (POMS)

This scale was developed by McNair et al. (15) to quickly identify mood swings and short-term changes. It is a scale in which participants rate a total of 65 qualifiers considering their preceding week. Each qualifier is rated as "not at all," "a little," "moderately," "quite a bit" or "extremely." The scale has 6 subscales: tension-anxiety, depression, anger-hostility, vigor, fatigue and confusion. In addition, there is a seventh score called Total Mood Disturbance, which is calculated by subtracting the score on vigor, which is a positively scored subscale, from the sum of the scores on the other 5 subscales. The validity and reliability study of this scale in Turkish was conducted by Selvi et al. (16).

Pittsburg Sleep Quality Index (PSQI)

The index was developed by Buysse et al. (17) in 1989. PSQI is a self-assessment scale. It consists of 24 questions, 19 of which are self-assessment questions, and 5 are questions to be answered by a roommate. Of the questions of the scale, 18 are categorized under 7 components:

Subjective sleep quality, sleep latency, sleep time, usual sleep efficacy, sleep disorder, sleep drug use and daytime dysfunction. Each component is rated between 0 and 3 points. The total score of the 7 components gives the total score of the scale. The total score ranges from 0 to 21. If the total score is greater than 5, it indicates "poor sleep quality." The reliability and validity study of the scale in Turkish was carried out by Ağargün et al. (18).

Statistical analysis:

We used IBM SPSS (Statistical Package for the Social Sciences) program version 22.0.0 to analyze data at the 95% confidence interval. Kolmogorov–Smirnov test was conducted to determine whether the data were normally distributed. Levene test was carried out to test the homogeneity and equality of variances. Student's T-tests and Mann-Whitney U tests were carried out to compare quantitative data. And Pearson Chi-Square tests were run to compare qualitative data. Pearson correlation analyses were conducted to determine the correlations between the data. Statistical significance was set at $p < 0.05$ level, and results were expressed in the form of mean ± standard deviation.

RESULTS

Both groups had similar demographic characteristics. Of the caregivers, 92% were a descendant of their patient, and all of them were first-degree relatives. The most difficult area to provide care in was the bathroom with 29.7% (Table 1).

Table 1: Characteristics of caregivers

Age		29.2 ± 11.6
Caregiving duration (years)		8.0 ± 6.1
Gender	Female	122 (100%)
	Male	0 (0.0%)
Degree of affinity	Child	92 (53.5%)
	Parent	10 (5.8%)
	Wife	8 (4.7%)
	Brother	12 (7.0%)

Forced care areas	Eat	9 (5.2%)
	Bathroom	28 (16.3%)
	Toilet	51 (29.7%)
	All	6 (3.5%)
	No	28 (16.3%)
Assistant individual	No	22 (12.8%)
	Yes	100 (58.1%)

The mean score of Zarit caregiver burden was 34.5 ± 10.4. Of the 122 caregivers, 0.8% suffered high caregiver burden, 26.2% suffered moderate caregiver burden, and 68% suffered mild caregiver burden, whereas 4.9% did not suffer any care burden. The mean CSAQ score was 5.1 ± 2.6. Of the caregivers, 54.9% were found to have caregiver burden according to the CSAQ. The mean total PSQI score was 4.6 ± 2.6 in the caregiver group and 4.0 ± 1.8 in the control group, and there was no significant difference between the scores (p = 0.371). There was no significant difference between the groups in terms of total POMS scores and its subscale scores (Table 2).

Table 2: PSQI and POMS scores between the groups

		Caregivers (n = 122)	Control (n = 50)
PSQI		4.6 ± 2.6	4.0 ± 1.8
POMS	Tension-anxiety	10.5 ± 6.4	10.4 ± 7.1
	Depression	8.9 ± 7.3	7.9 ± 5.9
	Anger-hostility	6.38 ± 6.8	5.6 ± 4.7
	Vigor	17.6 ± 4.9	16.4 ± 5.7
	Fatigue	6.2 ± 4.5	5.6 ± 4.4
	Confusion	8.2 ± 4.5	7.5 ± 3.7
	POMS Total	23.0 ± 25.1	20.7 ± 20.4

Results are presented as mean ± standard deviation (SD).

*p < 0.05; **p < 0.01

The Pearson's correlation analyses revealed that caregiver burden correlated positively with the tension-anxiety (r = 0.244, p = 0.007), depression (r = 0.429, p < 0.001), anger-hostility (r = 0.332, p < 0.001), fatigue (r = 0.525, p < 0.001), confusion (r = 0.394, p = 0.001) subscales of POMS and with total POMS scores (r = 0.409, p < 0.001). Similarly, the PSQI scores correlated positively with caregiver burden (r = 0.062, p = 0.004), total POMS scores (r = 0.436, p < 0.001), tension-anxiety (r = 0.386, p < 0.001), depression (r = 0.358, p < 0.001), anger-hostility (r = 0.369, p < 0.001), fatigue (r = 0.350, p < 0.001), and confusion (r = 0.369, p < 0.001) (Table 3).

Table 3: The Pearson's correlation analyses

	Caregiver burden	PSQI
Tension-anxiety	0.24*	0.39**
Depression	0.43**	0.36**
Anger-hostility	0.33**	0.37**
Vigor	0.05	0.08
Fatigue	0.53**	0.35**
Confusion	0.29*	0.40**
POMS Total	0.41**	0.44**

Results are presented as mean ± standard deviation (SD).

*$p < 0.05$; **$p < 0.01$

DISCUSSION

The aim of home care is to provide health care services and social services that are protective, preventive, curative and rehabilitative to individuals who are needy in terms of physical, social and mental aspects, in a continuous and effective way in the environment they live (19). In our country, it was first introduced in 2011 (19). With this practice, it has been aimed to provide regular and quality health care services by expert healthcare professionals to patients who are elderly, bed-dependent or disabled, who have chronic diseases such as joint-muscle diseases, who need post-operative care, or patients who are diagnosed with cancer, in their own home environment. In this context, health care professionals visit patients at their homes and provide

treatment. Nevertheless, the care of disabled individuals is provided primarily by their families. Although care for individuals by their relatives has a physically and psychologically positive effect on the well-being of the elderly, it was reported in some studies that 36% of caregivers of elderly people were unable to provide sufficient care (19,20,21). Caregivers face difficulties in helping the patient in the long term, can experience depression, affliction and excessive fatigue, and can become predisposed to physical, mental and social problems (22,23,24).

In the literature, care of elderly people and burden experienced by caregivers of such people have been studied in various groups. A number of studies have shown that physical and mental health of caregivers deteriorate, and they feel more exhausted in the presence of neurological diseases such as stroke, Parkinson's disease and Alzheimer's disease (5,22,25).

Mc Cullagh et al. (24) conducted a study on 232 stroke patients and their caregivers. The researchers proved that the significantly high anxiety and depression levels of the caregivers and the patients regressed after one year of follow-up. They used ZCBS to determine caregiver burden and found an average burden of 48 ± 13.2 points in the 3rd month (24). In another study (26), POMS and ZCBS were administered to caregivers of dementia patients. After the initial administration of the scales to the caregivers, the caregivers were subject to a short-term psychotherapy, and then, the scales were re-administered to the caregivers. The results showed no significant change in POMS, but a decrease in caregiving burden (26).

In line with the literature, the ZCBS score in our study was 34.5 ± 10.4, and it was found that 0.8% of the caregivers felt high caregiving burden, 26.2% felt moderate burden, and 68% felt mild burden.

In our study, 0.8% of the caregivers felt high caregiving burden, 26.2% felt moderate burden, and 68% felt mild burden. The mean caregiver burden score was 34.5 ± 10.4. The mean CSAQ score was found to be 5.1 ± 2.6. According to the CSAQ, 54.9% of the caregivers suffered caregiver burden.

Long-term caregiving burden can cause mental and physical changes in the caregiver. A significantly positive correlation was found between caregiver burden and caregiver anxiety and depression scores in the study of Ateş et al. (27). In another study, a positive correlation was found between anxiety and depression levels and sleep quality of caregivers (28). In our study, caregiver burden correlated positively with most POMS subscales — tension-anxiety, depression-dejection, anger-hostility, fatigue-inertia, confusion-bewilderment — as well as

with total POMS scores in line with the literature. Moreover, sleep disturbance correlated positively with caregiver burden, total POMS scores, tension-anxiety, depression-dejection, anger-hostility, fatigue-inertia, and confusion-bewilderment.

Our results showed that the participant caregivers suffered caregiving burden while carrying out their care activities, and that their daily life routines were adversely affected. As a result of increased caregiver burden, sleep quality and profiles of mood states were worsened, but contrary to our expectations, sleep quality and profiles of mood states of the caregivers were the same as those of the control group. This result can be explained by the fact that caring for a family is seen as a natural part of life over time. Although the caregiving burden increased in these people, it did not affect their mood and sleep quality.

In conclusion, it will be beneficial to initiate and develop institutional practices for minimizing the problems caregivers experience due to care. Additionally, making consultancy and training services for caregivers widespread and developing a corporate structure that provides continuous or partial support to caregivers will be useful in reducing caregiver burden.

The scope of our study includes only caregivers of home care patients, which can be considered a limitation of it. In addition, the fact that it was carried out in a home care unit in a single district is a limitation of our study. In this respect, larger scale studies can be planned by increasing the sample size.

DISCLOSURE STATEMENT

All authors declare no conflict of interest.

REFERENCES

1. TÜİK. Türkiye İstatistik Kurumu, İstatistiklerle Yaşlılar, 2018;27595.

2. Tezcan S, Seçkiner P. Türkiye'de demografik değişim; Yaşlılık perspektifi. HASUDER, 2012;1:19.

3. WHO. (2007b), Women, Ageing and Health: A Framework for Action: Focus on Gender, 11 January 2016,http://www.whqlibdoc.who.int/publications/2007/9789241563529_eng.pdf.

4. UN. United Nations, Department of Economic and Social Affairs Population Division. World Population Ageing 2013, ST/ESA/SER.A/348, 01 December 2015:22-37.

5. Zarit S. Family care and burden at the end of life. CMAJ 2004;170:1811-1812.

6. Duyar İ. İnsanda Yaşlılığın Evrimi: Yaşlılık Ne Zaman Başladı? 4. Ulusal Geriatri Kongre Kitabı, Antalya, 2005:48-52.

7. Kasuya RT, Polgar-Bailey P, Takeuchi R. Caregiver burden and burnout. Postgraduate Medicine 2000;108(7):119-123.

8. Sarı HY. Zihinsel engelli çocuğu olan ailelerde aile yüklenmesi. C.Ü Hem Yüksekokulu Der. 2007;11(2):1-7.

9. Dökmen ZY. Yakınlarına bakım verenlerin ruh sağlıkları ile sosyal destek algıları arasındaki ilişkiler. Ankara Üniversitesi Sosyal Bilimler Enstitüsü Dergisi 2012;3(1):3-38.

10. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist 1980;20:649-655.

11. Bergström AL, Eriksson G, von Koch L, Tham K. Combined life satisfaction of persons with stroke and their caregivers: associations with caregiver burden and impact of stroke. Health Qual Life Outcomes. 2011;11(9):1.

12. Özlü A, Yıldız M, Aker T. Zarit bakıcı yük ölçeğinin şizofreni hasta yakınlarında geçerlilik ve güvenilirlik çalışması. Nöropsikiyatri Arşivi 2009;46:38-42.

13. Health in Aging Foundation. Caregiver self assessment questionnaire 2015. Available from: https://www.healthinaging.org/tools-and-tips/caregiver-self-assessment-questionnaire

14. Aşkın A, Atar E, Şengül İ, Tosun A, Demirdal Ü, Elmalı F. Validity and reliability of the Turkish version of caregiver self assessment questionnaire. Disability and Rehabilitation 2019.

15. McNair DM, Lorr M, Droppleman LF. Manual for the Profile of Mood States. First ed. San Diego: Educational and Industrial Testing Service; 1971.

16. Selvi Y, Güleç M, Aydin A, Besiroglu L. Psychometric Evaluation of the Turkish language version of the profile of mood states (POMS). Journal of Mood Disorders 2011;1(4):152-161.

17. Buysse DJ, Reynolds CF, Monk TH. The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. Psychiatry Res 1989;28:193-213.

18. Ağargün MY, Kara H, Anlar O. Pittsburgh uyku kalitesi indeksi'nin geçerliği ve güvenirliği. Türk Psikiyatri Derg 1996;7:107-111.

19. Oğlak, S. Uzun süreli evde bakım hizmetleri ve bakım sigortası. Türk Geriatri Dergisi, 2007;10(2):100-108.

20. Bahar A, Parlar S. Yaşlılık ve evde bakım. Fırat Sağlık Hizmetleri Dergisi 2007; 2(4):32-39.

21. Şensoy N, Karabekir HS. Evde bakım: Olgu serisi. Geriatri ve Geriatrik Nöropsikiyatri Dergisi 2011;2(2-3):21-27.

22. Toseland RW, Smith G, Mccallion P. Family caregivers of the frail elderly, Handbook of Social Work Practice with Vulnerable and Resilient Populations. Columbia University Pres; 2001:324-332.

23. Morimoto T, Schreiner AS, Asano H. Care giver burden and health-related quality of life among Japanese stroke caregivers. Age and Ageing 2003;32:218-223.

24. Raina P, O'Donnell M, Rosenbaum P at al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics 2005;115:626-636.

25. McCullagh E, Brigstocke G, Donaldson N, Kalra L. Determinants of caregiving burden and quality of life in caregivers of stroke patients. Stroke 2005;36:2181-2186.

26. Sugiyama H, Kasanuki K, Yamagata M, Sato N, Ichimiya Y. Efficacy of group psychotherapy for caregivers of dementia patients. Alzheimer's & Dementia: The Journal of the Alzheimer's Association. 2017;13(7):1558-1558.

27. Ateş E, Canyılmaz E, Çakır NG, Yurtsever C, Yöney A. Kanser hastalarının ve onlara bakım veren kişilerin depresyon ve anksiyete durumlarının değerlendirilmesi. Ankara Medical Journal 2018;18(1):61-67.

28. Karabulutlu EY, Akyıl R, Karaman S, Karaca M. Kanser hastalarına bakım verenlerin uyku kalitesi ve psikolojik sorunlarının incelenmesi. Türk Onkoloji Dergisi 2013;2881:1-9