ORIGINAL RESEARCH

Sleep Quality and Factors Affect It in Caregivers of People with Dementia: A Cross-sectional Study

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Abstract

Objective: The aim of this study was to determine the sleep quality of caregivers of people with dementia (PwD) and the factors affecting it.

Materials and Methods: A cross-sectional study design was used. A total of 119 home-dwelling PwD and their primary caregivers were recruited from February-July 2019. Socio-demographic characteristics form, Pittsburg sleep quality, mini mental state examination (MMSE), neuropsychiatric inventory (NPI), activities of daily Living (ADL) and instrumental ADL (IADL), perceived stress scale (PSS), caregiver burden inventory (CBI), Beck depression inventory (BDI), and Charlson comorbidity index (CCI) were used. Descriptive statistics, t-test, Pearson's correlation and multinominal regression analysis were performed using SPSS version 25.0.

Results: The sleep quality of the caregivers was poor (10.70±3.663). Patients' MMSE, NPI, ADL and IADL; caregivers' PSS, CBI, BDI, and CCI together were a significant predictor of caregiver sleep quality (F=17.020; p<0.001). Eight variables together account for 55% of the variance in sleep quality. Predictive order of importance of variables on caregiver sleep quality was in the form of CCI (β=-0.396), BDI (β=0.292), MMSE score (β=-0.284), NPI (β=-0.239), PSS (β=0.196), CBI (β=0.108), ADL (β=-0.080), and IADL (β=0.052).

Conclusion: By determining the sleep quality and factors affecting of caregivers, it is considered that the caregivers will provide an opportunity for projects that will increase the sleep quality interventionally. Interventions to reduce caregiver depression, stress and burden can improve caregiver sleep quality; in addition, it is suggested that they will contribute to the sleep quality of caregivers in their attempts to improve the behavioral and cognitive functions of PwD.

Keywords: Sleep, caregivers, dementia

Introduction

The caregiving experience is usually seen as a chronic stressor with physical and psychological consequences (1). Caring for people with dementia (PwD) is like working in a full-time job, with family members spending an average of 21.9 hours per week caring for PwD. Caring is both emotionally and cognitively demanding and negatively affects caregivers' health (2). Sleep disturbance is a one of the significant health problems for a majority of caregivers of PwD (2,3). The prevalence rate of sleep problems was 9.4% among caregivers of PwD (4).

Since PwD stay awake at night and sleep during the day, their sleep-wake rhythms are disrupted, so when caregivers try to persuade the dementia patient to go back to bed, they will have to wake up many times and renounce their own sleep (5,6). When the caregivers cannot get enough sleep, their quality of life decreases, health indicators such as cortisol levels are adversely affected, and the risk of cardiovascular disease, obesity and diabetes increases (7). The frequency of depression and anxiety increases and cognitive function declines in caregivers with poor sleep quality (8-10). Sleep problems are significantly and positively associated with care recipients' disruptive behaviors (11). In addition these, it is stated that the main factor for 70% of caregivers to move their loved ones away from home and place them in nursing homes is insomnia (6). In a study conducted with individuals who had previously

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given care to PwD, caregivers quoted that they experienced insomnia, had nightmares, and could not reach pre-care sleep quality for ten years after care (7). Demographic characteristics of caregivers such as being female, highly educated caregivers are also independent predictors for carers' reporting greater sleep disturbance (5,9).

There is many of research have been found to determine the sleep of caregivers and the factors affecting it. But there are very few studies indicated both patients' and caregivers' related variables (8,11). Thus, in this study focused to identify the comprehensive factors of caregivers' sleep quality. In addition to this, there is a current systematic review which was investigate the effects of the sleep interventions for informal caregivers of PwD and none of the studies which was examined on the review from Turkish population (12). To the best of our knowledge, only one study (13) has reported findings of sleep quality of caregivers of PwD in Turkey. This can be a reason in the systematic review, there were no results of sleep interventions for caregivers of PwD from Turkey. In order to plan interventions to regulate and improve the sleep quality in caregivers PwD, it is necessary to determine the sleep quality of the caregivers and the comprehensive factors affecting them.

Materials and Methods

A cross sectional study design was used in this study.

Participants

Non-probability convenience sampling was used. Family members who gave primary care to PwD according to DSM-IV diagnostic criteria, lived in the same house with the patients, provided care for at least six months, and volunteered to participate in the study were included. The sample of the study consisted of 119 caregivers who applied to the dementia outpatient clinic of a university hospital between February-July 2019. A sample size of 119, effect size of 0.20, and alpha value of 0.05 were considered, and the power of study was found to be 0.83 by using G. Power.

Measures

Socio-demographic characteristics form

The form was prepared to obtain the socio-demographic information pf PwD and their caregivers (2,3,7,8,13).

Collected from PwD

Mini mental state examination (MMSE): It is used to access the cognitive function comprises orientation, learning, short-term memory, language use, comprehension, and basic motor skills. The total score ranges from 0 to 30. A low score indicates high cognitive impairment (14).

Neuropsychiatric inventory (NPI): NPI was used to evaluate the presence and severity of neuropsychiatric symptoms. The scores range from 0 to 144, with high scores corresponding to severe behavioral disorders (15).

Activities of daily living (ADL) and instrumental ADL (IADL): The ability of PwD to perform functional activities was assessed with Barthel ADL and Lawton's IADL.

Collected from Caregivers

Charlson comorbidity index (CCI): It was scored according to the weighted comorbidity index developed by Charlson et al. (16). The score obtained as a result of the scoring process for a patient to have more than one disease is called the Charlson comorbidity score (16).

Beck depression inventory (BDI): It was developed by Beck et al. (17) to measure the emotional, cognitive and motivational symptoms of depression in adolescents and adults. A minimum of zero and a maximum of 63 points can be obtained in the BDI inventory, and a high score indicates an excess of depression severity (18).

Perceived stress scale (PSS): It was developed by Cohen et al. (19). Consisting of 14 items in total, PSS is designed to measure how stressful a person's life is perceived to be. A score of 0-56 can be obtained in the PSS, and a high score indicates an excess of stress perception (19).

Caregiver burden inventory (CBI): It is a tool developed to measure the impact of caregiving on caregivers and their relatives (20). The inventory is a 24-item Likert-type (0-4) scale. The total score of each individual varies between 0 and 100. A high score indicates a high degree of burden, and a low score indicates a low degree of burden (21).

Pittsburg sleep quality (PSQ): It was developed by Buysse et al. (22) to determine sleep quality. The scale includes a total of 24 questions (19 of these self-evaluation). They determine the duration of sleep, the frequency and severity of special problems related to sleep latensive sleep. The 18 items scored were grouped into 7 component scores. Some of the components consist of a single substance, while others are obtained by grouping several substances. Each item is evaluated with a score between 0-3 points. A 0-21 points can be obtained from the scale. A total PSQI score of 5 or more indicates poor sleep quality.

Data collection

The study was conducted at a dementia outpatient clinic during follow-up of the PwD in the west part of Turkey. The caregivers had a face-to-face contact with the researchers lasted for 50 min. In the scales collected from PwD, the scores of the mental, behavioral and functional status evaluation scales made by

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their neurologist during the outpatient clinic visits were taken into account.

Statistics

Descriptive statistics, number, percentage distributions and correlation coefficients were evaluated. Multiple regression analysis was performed to determine the factors affecting the sleep quality of caregivers. Before the multiple regression analysis, the correlation of the influencing factors and the dependent variable with each other was determined using the multiple correlation test. The variance inflation factor (VIF) and tolerance were used to detect multicollinearity between the independent variables in the regression model. The independent variables with VIF>10 were removed from the model, and tolerance was less than 0.20. For all analysis, the level of statistical significance was set at $p \leq 0.05$. The SPSS 25.0 program was used to evaluate the data in the study.

Ethics

This study was carried out according to the Declaration of Helsinki (as revised 2013). This study was approved by the Ethics Committee of Dokuz Eylül University (2019/12-17, 2019.05.08). The purpose was explained to the caregivers participating in the study and their verbal and written consent were obtained.

Results

The socio-demographic and clinical characteristics of the PwD and their caregivers were shown in Table 1. The PSQ score of 119 caregivers of PwD was determined as 10.70±3.66 (1-17). A total PSQ score of five or more indicates poor sleep quality. The sleep quality of caregivers was compared according to the descriptive characteristics of PwD, and the results were given in Table 2. Sleep quality among the descriptive characteristics of caregivers were compared and the results were given in Table 3.

The relationship and significance between the clinical characteristics of PwD and their caregivers and sleep quality scores were shown in Table 4. A weak negative correlation was found between the MMSE of PwD and the sleep quality of caregivers (r=-0.333; p=0.000). A weak positive correlation was found between the sleep quality of NPI, ADL and IADL caregivers of PwD (r=0.302; r=0.234; r=0.269; p=0.001; p=0.015; p=0.003). A moderate positive correlation was found between caregivers' PSS, BDI and CCI and sleep quality (r=0.430; r=0.498; r=0.436; p<0.001). There was a weak positive correlation between CBI and sleep quality (r=0.397; p<0.001).

Multiple regression analysis was performed to predict the sleep quality of the caregivers according to the MMSE, NPI, ADL/IADL of PwD and the caregivers' PSS, CBI, BDI and CCI, and the results were given in Table 5. According to the results obtained, patients' MMSE, NPI, IADL, ADL, caregivers' PSS, CBI, BDI and

Table 1. Descriptive characteristics of people with dementia and caregivers		
People with dementia	**n**	**%**
Age		
65-69	13	10.9
70-74	22	18.5
75-79	29	24.4
80 and above	55	46.2
Gender		
Female	78	65.5
Male	41	34.5
Education level		
Illiterate	10	8.4
Literate	13	10.9
Primary school	31	26.1
Secondary school	14	11.8
High school graduate	27	22.7
University graduate	24	20.2
Marital status		
Married	58	48.7
Divorced/widowed/living apart	60	50.4
Acute/chronic disease		
Yes	59	49.6
No	60	50.4
Dementia stage		
1. Stage	48	40.3
2. Stage	35	29.4
3. Stage	36	30.3
Years of diagnosed with dementia		
Less than 1 year	36	30.3
1-5 years	51	42.9
6 years and above	32	26.9
Total	**119**	**100**
	X ± SD	**Min**	**Max**
Mini mental state examination	16.65±6.68	0	28
Neuropsychiatric inventory	50.20±28.19	10	130
Barthel activities of daily living	12.74±6.45	3	24
Lawton's instrumental activities of daily living	8.96±4.62	1	18
Caregivers	**n**	**%**	
Age			
30-39	12	10.0	
40-49	22	18.5	
50 and above	85	71.4	
Gender			
Female	91	76.5	
Male	28	23.5	

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Table 1. Continued			
Education level			
Literate	8	6.7	
Primary school	10	8.4	
Secondary school	14	11.8	
High school	25	21.0	
University	62	52.1	
Marital status			
Never married	21	17.6	
Married	79	66.4	
Divorced/widowed/living apart	19	16.0	
Antidepressant use			
Yes	20	16.8	
No	99	83.2	
Acute/chronic disease			
Yes	89	74.8	
No	30	25.2	
Relationship with patient			
Daughter	48	40.3	
Son	17	14.3	
Wife	28	23.5	
Brother	26	21.8	
Duration of living with the patient			
Since birth	11	9.2	
1-10 years	72	60.5	
11-20 years	9	7.6	
21-30 years	13	10.9	
31 years and above	14	11.8	
	X ± SD	**Min**	**Max**
Beck depression inventory	33.33±7.857	4	47
Perceived stress scale	44.02±15.405	3	74
Caregiver burden inventory	25.72±11.938	0	45
Charlson comorbid index	1.84±0.850	0	3
Pittsburgh sleep quality	10.70±3.663	1	17
SD: Standard deviation			

Table 2. Comparison of caregivers' Pittsburgh sleep quality scale scores based on descriptive characteristics of people with dementia					
Characteristics of people with dementia	**Pittsburgh sleep quality scale**			**Z/X²**	**p**
	X ± SD	**Min**	**Max**		
Age					
65-69	8.15±3.43	2	15	7.894[b]	0.048
70-74	10.32±3.83	4	16		
75-79	11.28±3.59	3	16		
80 and above	11.15±3.50	1	17		
Gender					
Female	10.60±3.90	1	17	–0.104[a]	0.917
Male	10.88±3.19	4	16		
Education level					
Illiterate	10.60±4.81	2	17	2.829[b]	0.729
Literate	10.08±5.25	1	16		
Primary school	11.23±3.21	3	16		
Secondary school	9.36±3.50	4	15		
High school graduate	10.78±3.65	4	16		
University graduate	11.08±2.84	5	16		
Marrital status					
Married	11.10±3.62	2	17	1.933[b]	0.380
Divorced/widowed/living apart	10.27±3.70	1	16		
Acute/chronic disease					
Yes	11.08±3.60	3	17	–1.070[a]	0.285
No	10.32±3.70	1	16		
Dementia stage					
CDR[c] 1	8.96±3.47	2	16	19.862[b]	0.000
CDR 2	11.97±3.57	1	16		
CDR 3	11.78±3.09	4	17		
Year duration with Dementia					
Less than 1 years	9.03±3.722	2	17	12.807[b]	0.002
1-5 years	11.67±3.502	1	16		
6 years and above	11.03±3.277	3	15		
[a]Mann-Whitney U test, [b]Chi-square test, [c]Clinical dementia rating, SD: Standard deviation					

CCI together were a significant predictor of caregiver sleep quality (F=17,020; p<0.001). Eight variables together account for 55% of the variance in sleep quality. Predictive order of importance of variables on caregiver sleep quality was in the form of CCI (β=-0.396), BDI (β=0.292), MMSE score (β=-0.284), NPI (β=-0.239), PSS (β=0.196), CBI (β=0.108), ADL (β=-0.080), and IADL (β=0.052).

Discussion

Sleep quality of the caregivers of the PwD in this study was poor. This finding is similar to other studies (2,3,5,7,8,10). Goa et al. (2) reported that the sleep quality of caregivers of PwD was significantly lower than that of non-caregivers in their meta-analysis. Obtaining similar results in the international literature is thought to be closely related to the dementia care process. Having a PwD in the same house undoubtedly requires day and night care. Since caregivers are constantly on the alert for their patients, it is considered that they experience constant interruptions in their sleep. In addition, the challenges of caregiving are well-known in the literature. It is thought that the difficulties and psychological outcomes of care may adversely affect the sleep quality of caregivers. In the current

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Table 3. Comparison of sleep quality according to the descriptive characteristics of caregivers

Characteristics of caregivers	Pittsburgh sleep quality scale			Z/X²	p
	X ± SD	Min	Max		
Age					
30-39	10.09±3.70	5	15	6.301[b]	0.098
40-49	8.91±4.12	1	15		
50 and above	11.24±3.43	3	17		
Gender					
Female	10.51±3.79	1	17	-0.934[a]	0.350
Male	11.32±3.17	3	15		
Education level					
Literate	11.43±4.86	3	17	2.746[b]	0.739
Primary school	11.40±4.11	2	16		
Secondary school	10.07±3.33	4	15		
High school graduate	10.36±3.94	1	16		
University graduate	10.73±3.48	3	16		
Marital					
Never married	10.52±3.78	3	16	1.833[b]	0.400
Married	10.95±3.72	1	17		
Divorced/widowed/ living apart	9.84±3.27	2	14		
Acute/chronic disease					
Yes	10.54±3.36	2	17	-1.275[a]	0.202
No	11.17±4.45	1	16		
Antidepressant use					
Yes	12.15±3.45	5	17	-1.852[a]	0.064
No	10.40±3.65	1	16		
Relationship with patients					
Daughter	10.90±4.08	1	17	3.609[b]	0.307
Son	11.94±2.56	8	15		
Wife	10.43±3.43	3	16		
Brother	9.81±3.61	3	15		
Duration of living with the elderly					
Since birth	9.64±4.82	3	16	1.308[b]	0.860
1-10 years	10.85±3.53	1	16		
11-20 years	10.00±4.30	2	16		
21-30 years	11.62±2.75	7	16		
31 years and above	10.36±3.83	3	17		
[a]Mann-Whitney U test, [b]Chi-square test, SD: Standard deviation					

Table 4. The relationship between the quality of sleep of the caregiver and the determined clinical characteristics of people with dementia and caregivers

Scales of determined clinical characteristics	Pittsburgh sleep quality	
	r	p
Mini mental state examination	-0.333	0.000
Neuropsychiatric inventory	0.302	0.001
Lawton's instrumental activities of daily living	0.269	0.003
Barthel activities of daily living	0.234	0.010
Perceived stress scale	0.430	0.000
Beck depression inventory	0.498	0.000
Caregivers burden inventory	0.397	0.000
Charlson comorbidity index	0.436	0.000

disease parameters and total PSQ scores of PwD similar to the findings of Chiu et al. (24) and Simpson and Carter (25). Rather than descriptive characteristics of the PwD, such as age, gender, and educational status, the variables of dementia stage and the duration of diagnosis affect the sleep of caregivers.

For caregivers, there was no statistically significant difference was found according to the age, gender, education level, marital status, presence of acute/chronic disease, antidepressant use, degree of closeness with the elderly cared for, duration of living with the elderly. In the current literature, studies examining the effects of descriptive characteristics of caregivers of PwD on the sleep quality of caregivers are limited and controversial (5,8,25). Park et al. (8) found the caregivers education was a significant factor on sleep quality. On the other hand, Gibson et al. (5) and Simpson and Carter (25) stated that like in this study caregiver education was not predictor for caregivers sleep quality.

In the study, although there was a weak negative correlation between the MMSE score of PwD and the sleep quality of their caregivers, a weak positive correlation was found between the scores obtained from NPI, from ADL and from IADL, and the sleep quality of caregivers.

Sleep problems of caregivers are strongly positively correlated with patients' neuropsychiatric symptoms (11). Specifically, caregiver sleep disturbance has been associated with patients' sleep disturbances, delusions, hallucinations, and emotional behavioral symptoms (irritation/aggression, depression, and anxiety). Decreased cognitive function and increased behavioral symptoms of PwD can be meaning that there is more and more need for support for patients about assisting personal care, monitoring their safety, comforting them to sleep. It is inevitable that PwD who have decreased cognitive functions, increased behavioral symptoms, and cannot perform their daily living activities are those who are in need of more care. It was concluded that sleep quality might be worse as caregivers may have more difficulty in the face of worsening cognitive,

study, most of the caregivers are over 50 years old and it is known that depending on aging, sleep quality decreases, total sleep duration shortens, night awakenings increase, rapid eye movement and slow wave sleep decreases (23). Therefore, it may be concluded that the sleep quality of the caregivers is low.

There was no significant relationship between the age, gender, educational status, marital status, presence of acute/chronic

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Table 5. Multiple linear regression analysis to estimate the quality of sleep of the caregiver according to the determined clinical characteristics of individuals with dementia and caregivers

	B	Sh.	β	t	p	R	R²	F	p
Mini mental state examination	-0.156	0.066	-0.284	-2.343	0.021	0.744	0.553	17.020	0.000
Neuropsychiatric inventory	-0.031	0.020	-0.239	-1.548	0.125				
Lawton's instrumental activities of daily living	0.029	0.165	0.052	0.178	0.859				
Barthel activities of daily living	-0.063	0.200	-0.080	-0.316	0.753				
Perceived stress scale	0.091	0.038	0.196	2.371	0.019				
Beck depression inventory	0.026	0.019	0.108	1.340	0.183				
Caregivers burden inventory	0.090	0.027	0.292	3.346	0.001				
Charlson comorbidity index	5.765	1.026	0.396	5.617	0.000				

functional and behavioral condition.

A moderate positive correlation was determined between the scores of the caregivers from the perceived stress and depression scale and the total score of the PSQ, and the difference was statistically significant. Similarly, Wang et al. (10) showed a weak positive correlation between caregivers' mean total score on PSQ and the score they obtained from the perceived stress scale, and found this relationship statistically significant. Consistently with this research, Park et al. (8) found that the depression was a significant factor on sleep quality in caregivers of PwD. Hamamcı et al. (13) revealed that the depression and anxiety levels of caregivers were related to their PSQ scores. A current, large and robust literature document emphasized the important rate of psychological distress (stress or depressive symptoms) among caregivers of PwD (1).

Peng et al. (3) examined sleep-related factors in caregivers of PwD and concluded that the sleep of caregivers is affected by chronic disease status, depression, caregiver burden, sleep hygiene behaviors. They also reported that caregivers with more chronic diseases and poor sleep hygiene conveyed worse sleep quality, and that poor sleep quality of caregivers disrupted their daytime functionality, causing them to use sleeping pills. Simón et al. (26) showed that the group of family caregivers who perceived the caregiving burden as high had a higher PSQ total score than the control group and the group of family caregivers who perceived the caregiving burden as low. These results are consistent with the current study. The Burden and comorbidity were associated with caregivers sleep quality. The caregivers have to manage their own illnesses. But most caregivers live more patient-oriented lives than their own. It is thought that this causes more burden and negatively affects the sleep quality of caregivers.

Study Limitations

Data on caregivers' sleep quality were collected through self-reported sleep. Dementia type was not assessed in the study; however, the sleep quality of caregivers may vary depending on the type of dementia. It did not identify exogenous variables

such as caffeine intake and environmental factors. In this study, the sleep quality of the patients was not measured. The sample was limited to monocentrically, and therefore the findings may not be generalizable to other parts of Turkey. These limitations could be taken into account in future studies.

Conclusion

It was concluded that the sleep quality of caregivers of PwD was poor. It was found that the sleep quality of the caregivers was not affected by the socio-demographic characteristics of the PwD and the caregivers, but by the MMSE, ADL, IADL and NPI scores of the PwD and the BDI, CBI, PSS, CCI scores of the caregivers.

It is recommended that health professionals should consider the needs of not only the patient but also the caregivers, and that they should pay more attention to their sleep problems by deeming the caregiver as a component in the difficult care process of the PwD. Caregiver burden, stress and depression should be evaluated, and it should be taken into account that the sleep quality of caregivers of PwD who have more behavioral symptoms with increased cognitive impairment and decreased functionality may be worse. Interventions to improve these factors, which we identified as a result of our study, may help improve the sleep quality of caregivers.

Ethics

Ethics Committee Approval: This study was carried out according to the Declaration of Helsinki (as revised 2013). This study was approved by the Ethics Committee of Dokuz Eylül University (2019/12-17, 2019.05.08).

Informed Consent: The purpose was explained to the caregivers participating in the study and their verbal and written consent were obtained.

Peer-review: Externally peer-reviewed.

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Authorship Contributions

Surgical and Medical Practices: B.A.S., Concept: B.A.S., Design: B.A.S., Data Collection or Processing: B.E., Analysis or Interpretation: B.A.S., B.E., Literature Search: B.A.S., B.E., Writing: B.A.S., B.E.

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