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Original Research Article

Quality of sleep among caregivers of Alzheimer disease patients: cross-sectional study from Saudi Arabia

Adel Ali Alhazzani[1]*, Mohammed Saeed Alqahtani[2]

[1]Neurology unit, Department of Medicine, College of Medicine, King Saud University, Riyadh, Saudi Arabia
[2]Neurology Resident, Armed Forces Hospital–Southern Region / King Fahad Hospital-Jeddah, Saudi Arabia

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***Correspondence:**
Dr. Adel Ali Alhazzani,
E-mail: aalhazzani2@ksu.edu.sa

ABSTRACT

Background: Alzheimer's disease (AD) is the most common cause of dementia and represents a major health burden. Characterized by gradual decline in cognitive function, leading to dependency and changes in behavior and personality. Patients with AD need continuous care, which may affect the caregiver's quality of life, including sleep quality. The aim of this study was to assess sleep quality among AD patients' caregivers and its determinants in Aseer region, Saudi Arabia.
Methods: A descriptive cross-sectional study was conducted among 110 caregivers of AD patients at Abha Mental Health Hospital. The caregivers' sleep quality was assessed using the Pittsburgh Sleep Quality Index (PSQI). A global PSQI cutoff value of 5 or higher was considered as indicative of poor sleep quality.
Results: Female caregivers' constituted 53.6% of the sample, and 50% were below the age of 40 years. The majority of the caregivers (64.5%) reported that they had experienced sleep disturbances during past month and 10% needed medication approximately three or more times a week to help them sleep. Almost two-thirds of the caregivers (60%) spent more than 10 hours daily with their patients. Regarding sleep hygiene, 40.9% of the caregivers rated their sleep quality as poor and only 10.9% had good sleep quality.
Conclusions: The burden on caregivers of AD patients is considerable and often under-recognized; in particular; most caregivers in the Saudi population were young and of working age. Poor sleep quality affected the caregivers' day life activities but typically remained undertreated.

Keywords: Sleep quality, AD, Caregivers

INTRODUCTION

Alzheimer's disease (AD) is a chronic neurodegenerative disease that typically has a slow progression but gradually worsens over time. It causes dementia in 60%–70% of cases.[1] The earliest presenting symptom is difficulty in remembering recent events.[2] In the advanced stages of the disease, symptoms can include problems with language, disorientation (which may include getting lost easily), mood swings, loss of motivation, inability to care for oneself, and behavioral issues.[3,4] As the patient's condition declines, they often withdraw from family and society. Gradually, bodily functions are lost, ultimately leading to death.[5] Although the speed of progression can vary, the typical life expectancy following diagnosis is three to nine years.[6,7]

Patients with AD usually lose their self-care ability and need caring. Caring for a person with AD or dementia often requires a team of people, be it for daily care giving, participation in decision making, or simply caring about a person with the disease. AD poses considerable challenges for both the patient and those who assume care giving responsibilities.[8,9] People with AD and related dementias are usually cared for by family members or friends. The majority (80%) of people with AD and related dementias receive care in their homes.[10] Each year, more than 16 million Americans provide more than 17 billion hours of unpaid care for family and friends with AD and related dementias.[11] In 2019 alone, these caregivers provided an estimated 18.5 billion hours of care. Approximately two-thirds of dementia caregivers are women, and about one in three caregivers (34%) is aged 65 years or older. Approximately one-quarter of dementia caregivers are "sandwich generation" caregivers; they care not only for an aging parent, but also for children under the age of 18 years.[12]

Care giving for AD patients is emotionally and cognitively exhausting. Many studies indicate that the caregivers' overall health is adversely altered.[13-15] Their cognitive functioning may also decline. Among these deteriorations, sleep disturbances exacerbate the observed changes to mental, physical, and cognitive health.[16,17]

The current study aimed to assess the sleep quality among caregivers of patients with AD in Aseer region, Saudi Arabia. Moreover, it attempted to identify the different predictors of sleep disturbance among the sampled caregivers.

METHODS

A descriptive cross-sectional approach including 110 caregivers of AD patients at Abha Mental Health Hospital, Saudi Arabia, was conducted during the period from January to September, 2018. Patient data were collected directly from the patients' medical records, while the caregivers were requested to complete a pre-structured questionnaire. The questionnaire was developed by the authors with the help of a literature review and expert consultation. An informed consent was obtained from all participants in the study. The collected data included caregivers' demographic information, such as age, gender, education level, work data, and relationship with the patient. The duration/time for daily care giving was calculated for each caregiver. Caregivers' quality of sleep was assessed using the Pittsburgh Sleep Quality Index (PSQI), a self-administered questionnaire that assesses sleep quality over a one-month time interval.[17] The measure consists of 19 individual items, creating 7 components that produce one global score. The component scores include perceived sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction. Each item is weighted on a 0–3 interval scale. The global PSQI score is then calculated by totaling the seven component scores, providing an overall score ranging from 0 to 21, where lower scores denote healthier sleep quality. The total score was categorized as good (score: 0–5), average (score: 6–13), or poor (score: 14–21) sleep quality.

The study was conducted in accordance with the Declaration of Helsinki, and the protocol was approved by the ethics and research committee of the college of Medicine, King Khalid University. After the data were extracted, they were revised, validated, coded, and statistically analyzed using IBM Statistical package for social sciences (SPSS) version 22 (SPSS, Inc., Chicago, IL). All the statistical analyses were conducted using the two-tailed test. P value of less than 0.05 was considered to be statistically significant. Descriptive analysis based on frequency and percent distribution was conducted for all variables, including the caregivers' demographic data and sleep quality items. Univariant relations between caregivers' bio-demographic data and their sleep quality were assessed using the Pearson Chi-squared test.

RESULTS

A sample of 110 caregivers of AD patients was considered in this study. Female caregivers' constituted 53.6% of the sample, and 50% were below the age of 40 years.

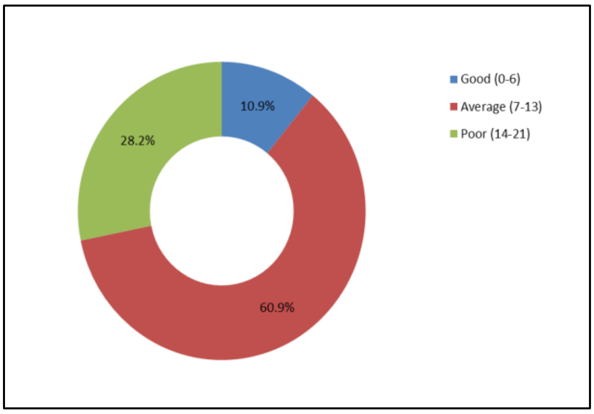

Figure 1: Overall sleep quality among caregiver of AD patients in Aseer region, Saudi Arabia.

Moreover, 69.1% of the caregivers were married. Approximately 69% of the caregivers were the patients' siblings, and 11.8% were spouses. Only four of the caregivers were non-Saudi, and 40% were university graduates, while 30.9% had completed the intermediate education level. As for work status, 40% of the caregivers were working, and 44.5% reported a monthly income below SR3000. Moreover, 60% of the caregivers spent more than 10 hours daily with their patients, and 46.4% were anxious about contracting the same disease or beginning to present the same symptoms as their patients (Table 1).

Regarding sleep hygiene (Table 2), 40.9% of the caregivers rated their sleep quality as poor, 30% reported that they need at least 30 minutes to fall asleep each night and only 10.9% had good sleep quality. Further, 68.2% of the caregivers reported sleeping for less than 6 hours daily, and 26.4% of them were found to have a habitual sleep efficacy of less than 65%. Exactly 64.5% of the caregivers reported having had sleep disturbances during the past month, and 10% required medication three or more times a week to help them sleep. Daytime functions were affected due to sleep disturbances among 54.6% of the participants. In total, 28.2% and 10.9% of the caregivers reported poor and good sleep quality, respectively (Figure 1).

Table 1: Personal data of caregiver for AD patients in Aseer region, Saudi Arabia.

Personal data		No	%
Gender	Male	51	46.4
	Female	59	53.6
Age in years	< 30 years	27	24.5
	30-39	28	25.5
	40-49	24	21.8
	50+	31	28.2
Marital status	Married	76	69.1
	Not married	34	30.9
Relation to the patient	Spouse	13	11.8
	Son/ daughter	76	69.1
	Brother/ sister	3	2.7
	Parents	7	6.4
	Others	11	10.0
Nationality	Saudi	106	96.4
	Non Saudi	4	3.6
Educational level	Illiterate	21	19.1
	Primary	11	10.0
	Intermediate	34	30.9
	University/ more	44	40.0
Work	Working	44	40.0
	Not working	54	49.1
	Student	12	10.9
Monthly income	<3000 SR	49	44.5
	3000-6000 SR	22	20.0
	6000-10000 SR	18	16.4
	> 10000 SR	21	19.1
Duration spent with patent daily	1-4	17	15.5
	5-9	27	24.5
	10+	66	60.0
Do you have anxiety and fear to get same disease and symptoms your patient has?	Yes	51	46.4
	No	59	53.6

Table 2: Sleep hygiene of different PSQI domains among caregiver of AD patients.

Domain	Items		No	%
Subjective sleep quality	**How would you rate your sleep quality overall**	Very good	16	14.5
		Fairly good	49	44.5
		Fairly bad	22	20.0
		Very bad	23	20.9
Sleep latency	**How long (in minutes) has it usually take you to fall asleep each night**	< 15 minutes	16	14.5
		16-30	39	35.5
		31-60	30	27.3
		> 60 minutes	25	22.7
	Cannot get to sleep within 30 minutes	Never	22	20.0
		Less than once a week	23	20.9
		Once / twice a week	27	24.5
		Three or more times a week	38	34.5
Sleep duration	**Hours of actual sleep at night**	> 7 hours	8	7.3
		6-7 hours	27	24.5
		5-6 hours	35	31.8

Continued.

Domain	Items		No	%
		< 5 hours	40	36.4
Habitual sleep efficacy	**Habitual sleep efficacy %**	>85%	13	11.8
		75%-85%	33	30.0
		65%-74%	35	31.8
		<65%	29	26.4
Sleep disturbances	**Sleep disturbances during past month**	Never	1	0.9
		Rarely	38	34.5
		Sometimes	57	51.8
		Usually	14	12.7
Use of sleeping medication	**Had medication to help you to sleep**	Never	58	52.7
		Less than once a week	27	24.5
		Once / twice a week	14	12.7
		Three or mor times a week	11	10.0
Daytime dysfunction	**Daytime dysfunction level**	Never	18	16.4
		Very slight	32	29.1
		Somewhat	42	38.2
		High	18	16.4

Table 3: Distribution of sleep quality according to caregiver personal characteristics.

Factors		Sleep quality				P value
		Average/ good		**Poor**		
		No	**%**	**No**	**%**	
Gender	Male	36	70.6	15	29.4	0.790
	Female	43	72.9	16	27.1	
Age in years	< 30 years	19	70.4	8	29.6	0.345
	30-39	23	82.1	5	17.9	
	40-49	18	75.0	6	25.0	
	50+	19	61.3	12	38.7	
Marital status	Married	53	69.7	23	30.3	0.468
	Not married	26	76.5	8	23.5	
Relation to the patient	Partner	7	53.8	6	46.2	0.058
	Son/ daughter	55	72.4	21	27.6	
	Brother/ sister	3	100.0	0	0.0	
	Father/ mother	6	85.7	1	14.3	
	Others	8	72.7	3	27.3	
Nationality	Saudi	78	73.6	28	26.4	0.034*
	Non Saudi	1	25.0	3	75.0	
Educational level	Illiterate	15	71.4	6	28.6	0.473
	Primary	7	63.6	4	36.4	
	Intermediate	22	64.7	12	35.3	
	Secondary	0	0.0	0	0.0	
	University/ more	35	79.5	9	20.5	
Work	Working	34	77.3	10	22.7	0.410
	Not working	38	70.4	16	29.6	
	Student	7	58.3	5	41.7	
Monthly income	<3000 SR	35	71.4	14	28.6	0.659
	3000-6000 SR	15	68.2	7	31.8	
	6000-10000 SR	15	83.3	3	16.7	
	> 10000 SR	14	66.7	7	33.3	
Duration spent with patient daily	1-4	14	82.4	3	17.6	0.042*
	5-9	22	81.5	5	18.5	
	10+	43	65.2	23	34.8	
Anxious to get same disease and symptoms your patient has.	Yes	34	66.7	17	33.3	0.264
	No	45	76.3	14	23.7	

P: Pearson X^2 test, * $p<0.05$ (significant)

Table 3 relates the caregivers' sleep quality with their sociodemographic data. Poor sleep quality was reported among 29.4% of the male caregivers compared to 27.1% of their female counterparts, and these results were not statistically significant. As for age, 38.7% of caregivers aged above 50 years had poor sleep quality compared to 29.6% of those aged below 30 years. Moreover, 30.3% of the married caregivers had poor sleep quality compared to 23.5% of the unmarried caregivers. Poor sleep quality was also noted among 75% of the non-Saudi caregivers compared to 26.4% of their Saudi counterparts, and the results were statistically significant (p=0.034). Regarding the caregivers' work, poor sleep quality was recorded among 29.6% of non-working caregivers compared to 22.7% of the working group. With regard to the time spent with the patient daily, 34.8% of those who spent more than 10 hours a day had poor sleep quality compared to 17.6% of those who spent 1–4 hours daily, and this result was statistically significant (p=0.042).

DISCUSSION

Care for patients with Alzheimer dementia is burdensome and demanding compared with care giving for patients with other disorders due to the progressive nature of the former in terms of the impairment it causes in cognitive and physical functioning. Sleep abnormalities are frequent in neuropsychiatric diseases such as AD and Parkinson disease (PD).[18] Sleep disturbances often affect the quality of life of these patients and their caregivers alike because of decreased daytime attention and altered circadian rhythms, which in turn disturb the sleep habits of caregivers and increase their burden.[19,20]

This study aimed to assess the sleep quality of caregivers for patients with AD and identify its determinants. The results revealed that while slightly more than a quarter of the caregivers had poor sleep quality, the majority had average sleep quality. The most affected sleep component was sleep latency, as nearly half of the caregivers required a long time to fall asleep more than three times a week. Moreover, sleep efficacy was poor among more than half of the caregivers, but sleep disturbances were recorded among very few of them. Further, daytime dysfunction was high among less than 16% of the caregivers, possibly due to the overall changes in sleep hygiene. This result indicates that about 40% of the patients subjectively rated their sleep quality as either fair or very poor. Regarding the determinants of sleep quality, poor quality was more common among non-Saudi caregivers, who are mostly employed for care giving and spend more time with AD patients. Poor sleep quality was also evident among more than one-third of the caregivers who spent 10 hours or more with their patients. Caregivers who were spouses also experienced somewhat poorer sleep quality than their counterparts, which can also be explained by their spending a considerable amount of time with their affected partners.

Much of the literature on sleep hygiene among AD patients' caregivers reports sleep disturbances in the caregivers and observes that several factors are directly related to the disease, including nocturnal agitation and sun downing, insomnia, sleep-related movement disorders, obstructive sleep apnea, circadian rhythm disorders, and medication-induced sleep impairment.[18,21,22] Cupidi et al conducted a cross-sectional study on 40 patients with probable AD, 40 patients with PD without dementia, and their primary caregivers during their routine visits to outpatient clinics.[23] The researchers reported that 18 AD (45%), 22 PD (55%), and 45 (30%) controls reported poor sleep quality. The mean global PSQI score of the PD patients was 6.25 (total score: 21). Sleep disturbances in caregivers of persons with dementia were studied by McCurry et al via literature review, which reported sleep disturbances in 19% [25] to 68% of caregivers.[24,2]

Alhazzani et al conducted a cross-sectional study in Saudi Arabia and revealed that AD caregivers tended to be sons or daughters (69.1%) or spouses (11.8%) and that the majority of caregivers had poor quality of sleep.[27] The global PSQI score positively correlated with the duration of caregivers' daily stay with AD patients (r=0.272, p=0.004), but it did not correlate significantly with either the caregivers' or the patients' ages. Alshammari et al conducted a study in Saudi Arabia to discover the characteristics of informal caregivers of elderly patients; identify the socioeconomic, psychological, and physical consequences experienced by informal caregivers; and measure their burdens and needs.[28] The researchers concluded that most caregivers (78.1%) suffered from musculoskeletal problems. The mean Zarit Burden Interview score was 31.3, which indicated a moderate burden. More than half of these caregivers requested blood pressure- (55.6%) and blood sugar-measuring devices (53%). Three quarters (74.9%) of these caregivers wanted educational training to cope with emergencies. Most caregivers expressed a need for frequent healthcare for themselves (58.4%) and a home health visit service (72.9%) to support them in the care of their elderly.

It is evident that sleep quality is inadequate among the caregivers of persons with AD. Many precipitating, predisposing, and perpetuating factors, including poor sleep routines and increased physical and psychological burdens on the caregivers, are frequently associated with sleep complaints. The findings of this study should be viewed in light of certain limitations, including the small sample size, the fact that it was conducted in one region only, and the lack of objective measures of sleep quality.

CONCLUSION

The burden on caregivers of AD is huge and often under-recognized. The sleep quality of AD patients' caregivers in this study was not adequate; in particular, most caregivers were young and of working age. Poor sleep quality affected the caregivers' day life activities, but typically remained undertreated. Continuous training and education for caregivers with regard to the nature of AD and their patients' needs will help improve caregivers' quality of life in general and sleep hygiene in particular. Furthermore, caregivers should learn how to cope with the stress and exhaustion that they face during their care giving. It is crucial to allocate the resources to raise awareness about the burden of caregivers to patients with AD and to promptly identify, treat, and support them as much as the patients themselves.

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