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The relationship between sleep quality and fatigue levels in relatives of patients hospitalised in palliative care unit

Tugba Kavalali Erdogan*, Nursing Department, Health Science Faculty, Ondokuz Mayıs University, Samsun
55200, Turkey **ORCID:** <https://orcid.org/0000-0001-7903-4905>

Zeliha Koc, Health Science Faculty, Ondokuz Mayıs University, Samsun 55200, Turkey.
ORCID <https://orcid.org/0000-0002-8702-5360>

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Abstract

This study was carried out as a descriptive and cross-sectional study to find out the relationship between sleep quality and fatigue levels in relatives of patients hospitalised in the palliative care unit. This study was carried out with the participation of relatives of 80 patients who were receiving care and treatment in the palliative care unit, who formed the study group, while the relatives of 80 patients who were receiving care and treatment in internal medicine and surgery clinics formed the control group. In the study, the data were collected by using patient and patient relatives descriptive information form, Pittsburgh Sleep Quality Index (PSQI) and Piper Fatigue Scale (PFS). PSQI and PFS median scores of patient relatives in the study group were 8 (0–16) and 4.95 (1–9), respectively, while PSQI and PFS median scores of patient relatives in the control group were 10 (2–16) and 6.09 (2–9), respectively. In line with the results found in the study, patient relatives were found to have moderate fatigue and poor quality of sleep.

Keywords: Fatigue, patient, patient relative, palliative care, quality of sleep.

* ADDRESS FOR CORRESPONDENCE: **Tugba Kavalali Erdogan**, Nursing Department, Health Science Faculty, Ondokuz Mayıs University, Samsun 55200, Turkey. *E-mail address:* tugbakavalali@hotmail.com

1. Introduction

The average life expectancy and the rate of elderly population have been increasing gradually in recent years in the world and in our country. Prolongation of life expectancy causes an increase in the number of people struggling with chronic diseases such as cancer, neurological diseases and cardiovascular diseases [1]. Chronic diseases are diseases which require long-term care, protection and rehabilitation and which can cause irreversible, permanent and progressive damage [2]. With the increase in chronic diseases, survival time from diseases has increased and, therefore, the number of patients who need professional healthcare has also increased. This situation has also increased the need for palliative care [1]. Palliative care is a type of approach that increases the quality of life in individuals starting from the moment they are diagnosed and provides early detection and effective evaluation of all problems related to life-threatening chronic diseases [3], [4]. Meeting the physical, spiritual and psychosocial needs of the patient and the family during both treatment and mourning process and communicating effectively with the patient and family members are among the basic principles of palliative care [3], [5]. For this reason, it is extremely important to evaluate the patient and family/relative together. Family members/patient relatives providing care to individuals with chronic disease play an important part in the treatment and care process. In this difficult process, patient relatives have complex tasks such as monitoring and controlling the symptoms related to their patients' diseases and treatments, finding solutions for various problems and making decisions, organising the environment, ensuring patient safety and meeting self-care needs [6], [7].

It is also reported in the literature that caregivers carry out various activities to increase the well-being of patients such as keeping hope, providing emotional support, maintaining relationships with families, conducting religious ceremonies/rituals and meeting their needs [8], [9]. However, it is also reported that patient relatives who are actively included in the care process of patients experience problems such as anxiety, depression, hopelessness, fear, exhaustion, fatigue and sleep problems, depending on the changes that take place in their daily lives [6], [7], [10]–[15]. It is reported in the literature that especially caregivers with poor sleep quality have more fatigue, anxiety, depression, anger, musculoskeletal and gastrointestinal system diseases [16]–[18]. In palliative care, it is very important to meet the needs of patient relatives/caregivers to be able to provide integrative nursing care [7].

Palliative care nurses providing holistic care by considering the needs of patient relatives, such as sleeplessness and fatigue, contribute to increasing the life quality of patients and their relatives in addition to increasing the quality of nursing care.

1.1. *Objective of the study*

This study was planned to find out the relationship between sleep quality and fatigue levels in relatives of patients hospitalised in palliative care unit. Answers were sought to the following questions in this study:

- What are the sociodemographic and clinical characteristics of relatives of patients hospitalised in palliative care unit?
- How is the sleep quality in relatives of patients hospitalised in palliative care unit?
- How are the fatigue levels in relatives of patients hospitalised in palliative care unit?
- Is there a relationship between fatigue levels and sleep quality in relatives of patients hospitalised in palliative care unit?

2. Methods

2.1. Place and time of the research

This descriptive, cross-sectional and correlational study was carried out with the participation of relatives of patients who were receiving care and treatment in the palliative care unit and internal and surgical medicine clinics of a hospital in the Central Black Sea region, which is in the north of Turkey.

2.2. Population and sample of the research

The study was carried out with the participation of 160 relatives of patients who were receiving care and treatment in the palliative care unit and internal and surgical medicine clinics and who were determined with non-probable sampling method. 80 relatives of patients who were receiving care and treatment in the palliative care unit constituted the study group and 80 relatives of patients who were receiving care and treatment in internal and surgical medicine clinics constituted the control group. Male or female patient relatives who were ≥ 18 years of age, who had an educational level of at least literate, who did not have a psychological or mental problem, who could communicate verbally, who were primarily responsible for patient care and who volunteered to participate were included in the study.

2.3. Tools for data collection

The data in the study were collected by using patient and patient relatives information form, Pittsburgh Sleep Quality Index (PSQI) and Piper Fatigue Scale (PFS). The survey form consists of 23 questions, including the sociodemographic and clinical characteristics of the patients and the sociodemographic, clinical and caregiving characteristics of patient relatives. The survey form was tested with a pre-application on a group of 10 individuals and the patient relatives who participated in the pilot study were not included in the sample. The patient relatives in the study were informed that it was their decision to participate in the study and the data collected in the study would be used only within the scope of the study and their verbal consents were taken.

2.3.1. Pittsburgh Sleep Quality Index (PSQI)

The PSQI is a self-report scale developed by Buysse et al. [19] and it provides detailed information about the sleep quality of the individual within a period of a month and the type and severity of sleep disturbance. Turkish validity and reliability study of the scale was conducted by Agargun et al. [20].

The scale consists of 24 questions and 7 components as subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, sleep medication use and daytime dysfunction. The total score range that can be obtained from the scale varies between 0 and 21. A score higher than 5 means that the individual has poor sleep quality, while Cronbach's alpha coefficient of the scale was found as 0.80 in the validity and reliability study conducted by Agargun et al. [20]; Cronbach's alpha coefficient was found as 0.72 in the control group and as 0.61 in the study group in the present study. Permission was taken from Agargun et al. to use the PSQI

2.3.2. Piper Fatigue Scale (PFS)

The PFS is a multidimensional scale developed by Piper et al. [21] to examine the fatigue symptoms of healthy and sick individuals. Turkish validity and reliability of the study was conducted by Can [22]. The scale consists of 22 questions and 4 factors as behavioural/severity, sensory, affective meaning and cognitive/mood. The scale also includes five questions (questions 1, 24, 25, 26 and 27) which are not used in the calculation of fatigue score but used in the assessment of data related with fatigue. These questions enable individuals to express their thoughts related with fatigue. An increased total score shows increased fatigue level. According to validity and reliability analyses conducted by Can

[22], Cronbach’s alpha coefficient of the scale was found as 0.94, while it was found as 0.99 in the control group and as 0.96 in the study group in the present study.

2.4 Data collection

The data were collected by the researchers through the face-to-face interview method with patient relatives. After the patient relatives were explained about the study, they were given the survey form. The patient relatives were informed that it was their decision to participate in the study, their names would not be written on the survey forms and the data collected in the study would be used only within the scope of the study. Data collection process lasted for about 15 minutes.

2.4. Data analysis

Statistical analysis of the data relating the patient relatives included in the study was carried out by using SPSS 21.0 package programme. Normality test of the quantitative data was analysed with Kolmogorov–Smirnov. Kruskal–Wallis test and Mann–Whitney U test were used in the analysis of the data which were not normally distributed. The results were presented as frequency, percentage, median, minimum and maximum. The relationship between the scales and the factors was examined with Spearman’s correlation analysis. Significance level was considered as $p < 0.05$.

3. Results

The distribution of the sociodemographic and clinical characteristics of the patient relatives and the patients cared for in the study and control group is shown in Table 1. It was found that 46.9% of the patients were female, 53.1% were male, 25% were high school graduates, 24.4% were primary school graduates, 62.5% were married, 35% were living with their spouses and children, 28.8% were diagnosed with cancer, 20% were diagnosed with renal failure, 8% were diagnosed with neurological disease, 71.9% had a chronic disease, 29.2% had hypertension and 25% had diabetes (Table 1).

Table 1. Sociodemographic and clinical characteristics of the patients in the study and control groups

		Control		Study		Total	
Demographic and clinical characteristics		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Age groups	20–45	18	22.5	10	12.5	28	17.5
	46–70	34	42.5	30	37.5	64	40.0
	≥71	28	35.0	40	50.0	68	42.5
Gender	Female	37	46.3	38	47.5	75	46.9
	Male	43	53.8	42	52.5	85	53.1
Educational status	Illiterate	12	15.0	12	15.0	24	15.0
	Literate	9	11.3	12	15.0	21	13.1
	Primary	28	35.0	11	13.8	39	24.4
	Secondary	14	17.5	11	13.8	25	15.6
	High school	15	18.8	25	31.3	40	25.0
	University	2	2.5	9	11.3	11	6.9
Marital status	Married	50	62.5	50	62.5	100	62.5
	Single	30	37.5	30	37.5	60	37.5
Who the patient lives	Spouse	15	18.8	21	26.3	36	22.5
	Children	13	16.3	15	18.8	28	17.5

with	Spouse and children	28	35.0	28	35.0	56	35.0	
	Alone	23	28.8	12	15.0	35	21.9	
	Relatives	1	1.3	4	5.0	5	3.1	
Current diagnosis	Diabetes	10	12.5	-	-	10	6.3	
	Asthma	6	7.5	4	5.0	10	6.3	
	Renal failure	32	40.0	-	-	32	20.0	
	Cancer	2	2.5	44	55.0	46	28.8	
	Hypertension	6	7.5	-	-	6	3.8	
	Cardiac failure	5	6.3	3	3.8	8	5.0	
	Ulcer	5	6.3	-	-	5	3.1	
	Dementia	3	3.8	7	8.8	10	6.3	
	Neurological disturbance	11	13.8	2	2.5	13	8.1	
	Respiratory failure	-	-	7	8.8	7	4.4	
	Nutritional disorder	-	-	13	16.3	13	8.1	
	When the diagnosis was taken	0–6 months	23	28.8	15	18.8	38	23.8
		7–13 months	13	16.3	13	16.3	26	16.3
		14–19 months	4	5.0	23	28.8	27	16.9
20–25 months		4	5.0	13	16.3	17	10.6	
26–31 months		3	3.8	6	7.5	9	5.6	
≥32 months		33	41.3	10	12.5	43	26.9	
The state of having a chronic disease	Yes	63	78.8	52	65.0	115	71.9	
	No	17	21.3	28	35.0	45	28.1	
Chronic disease diagnosis	Cardiac disease	29	19.0	9	10.8	38	16.2	
	Diabetes mellitus	41	26.8	18	21.7	59	25.0	
	Hypertension	41	26.8	28	33.7	69	29.2	
	Atherosclerosis	10	6.5	3	3.6	13	5.5	
	Renal failure	10	6.5	4	4.8	14	5.9	
	Asthma	12	7.8	12	14.5	24	10.2	
	Chronic obstructive pulmonary disease	8	5.2	9	10.8	17	7.2	
	Other	2	1.3	83	100.0	2	0.8	

It was found that 66.2% of the patient relatives in the study group were female, 33.8% were male, 62.5% were single, 53.8% were high school graduates, 52.5% were unemployed, 30% were housewives, 88.8% had a nuclear family, 58.8% lived in the same house with their patient, 78.8% did not have any chronic disease, 37.5% had diabetes, 25% had asthma, 63.8% got help from someone else during patient care, 27.5% had caregiving duration of 0–3 months, the health of 42.5% was partly affected during the caregiving process. It was also found that 81.3% experienced sleep problems during the time they stayed in the hospital, 29.5% experienced sleep problems because their patient woke up frequently and 23.7% experienced sleep problems due to worrying about the disease (Table 2).

It was found that 77.5% of the patient relatives in the control group were female, 22.5% were male, 88.8% were single, 32.5% were primary school graduates, 63.8% were unemployed, 56.3% were housewives, 87.5% had a nuclear family, 53.8% did not live in the same house with their patient, 53.8% did not have any chronic disease, 47.3% had hypertension, 27.3% had diabetes, 52.5% got help from someone else during patient care, 33.8% had caregiving duration of 0–3 months, the health of 63.8% was partly affected during the caregiving process. It was also found that 93.8% experienced sleep problems during the time they stayed in the hospital, 23.6% experienced sleep problems due to the unfamiliar environment, 21.7% experienced sleep problems due to noise and 15.6% experienced sleep problems because their patient woke up frequently (Table 2).

Table 2. Sociodemographic and clinical characteristics of the patient groups in the study and control group

		Control		Study		Total	
Patient relative characteristics		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Age groups	20–40	23	28.8	41	51.3	64	40.0
	41–60	48	60.0	34	42.5	82	51.3
	≥61	9	11.3	5	6.3	14	8.8
Gender	Female	62	77.5	53	66.3	115	71.9
	Male	18	22.5	27	33.8	45	28.1
Marital status	Married	7	8.8	22	27.5	29	18.1
	Single	71	88.8	50	62.5	121	75.6
	Divorced	2	2.5	8	10.0	10	6.3
Educational status	Literate	20	25	2	2.5	18	11.3
	Primary	26	32.5	8	10.0	34	21.3
	Secondary	17	21.3	8	10.0	25	15.6
	High school	10	12.5	43	53.8	53	33.1
	University	7	8.8	19	23.8	26	16.3
Employment status	Yes	29	36.3	42	52.5	71	44.4
	No	51	63.8	38	47.5	89	55.6
Occupation	Housewife	45	56.3	24	30.0	69	43.1
	Worker	13	16.3	14	17.5	27	16.9
	Officer	9	11.3	12	15.0	21	13.1
	Self-employed	4	5.0	16	20.0	20	12.5
	Retired	8	10.0	5	6.3	13	8.1
	Student	1	1.3	9	11.3	10	6.3
Social security	Yes	79	98.8	59	73.8	138	86.3
	No	1	1.3	21	26.3	22	13.8
Place of residence	City	37	46.3	38	47.5	75	46.9
	Town	37	46.3	42	52.5	79	49.4
Family structure	Nuclear	70	87.5	71	88.8	141	88.1
	Extended	10	12.5	9	11.3	19	11.9
The state of having children	Yes	71	88.8	56	70.0	127	79.4
	No	9	11.3	24	30.0	33	20.6

Income status	Income < expense	13	16.3	24	30.0	37	23.1
	Income = expense	42	52.5	52	65.0	94	58.8
	Income > expense	25	31.3	4	5.0	29	18.1
Relation with the patient	Spouse	23	28.8	18	22.5	41	25.6
	Parent	38	47.5	32	40.0	70	43.8
	Sibling	5	6.3	3	3.8	8	5.0
	Child	9	11.3	1	1.3	10	6.3
	Other	5	6.3	26	32.5	31	19.4
The state of living in the same house with the patient	Yes	37	46.3	47	58.8	84	52.5
	No	43	53.8	33	41.3	76	47.5
The state of having a chronic disease	Yes	43	53.8	17	21.3	60	37.5
	No	37	46.3	63	78.8	100	62.5
The chronic disease if the answer is yes	Cardiac disease	7	12.7	4	16.7	11	13.9
	Diabetes mellitus	15	27.3	9	37.5	24	30.4
	Hypertension	26	47.3			26	32.9
	Atherosclerosis	1	1.8	2	8.3	3	3.8
	Renal failure			1	4.2	1	1.3
	Asthma	1	1.8	6	25.0	7	8.9
	Chronic obstructive pulmonary disease	3	5.5	2	8.3	5	6.3
The state of getting support from someone else	Yes	42	52.5	51	63.8	93	58.1
	No	38	47.5	29	36.3	67	41.9
Who the support is received from if the answer is yes	Father	2	2.5	3	3.8	5	3.1
	Sibling	21	26.3	16	20.0	37	23.1
	Mother	4	5.0	5	6.3	9	5.6
	Child	9	11.3	13	16.3	22	13.8
	Spouse	2	2.5	4	5.0	6	3.8
	Relative	4	5.0	8	10.0	12	7.5
The state of providing care to someone else in the family	Yes	9	11.3	9	11.3	18	11.3
	No	71	88.8	71	88.8	142	88.8
Duration of care giving	0–3 months	27	33.8	22	27.5	49	30.6
	3–6 months	8	10.0	19	23.8	27	16.9
	6–9 months	8	10.0	16	20.0	24	15.0

	9–12 months	13	16.3	9	11.3	22	13.8
	Longer than 1 year	24	30.0	14	17.5	38	23.8
The time when the patient needed care most	Night	29	36.3	27	33.8	56	35.0
	Day	51	63.8	53	66.3	104	65.0
Health status being affected by care role	Yes	17	21.3	12	15.0	29	18.1
	No	12	15.0	34	42.5	46	28.8
	Partly	51	63.8	34	42.5	85	53.1
The state of experiencing sleep problem	Yes	75	93.8	65	81.3	140	87.5
	No	5	6.3	15	18.8	20	12.5
Causes of sleep problem	Noise	46	21.7	15	10.8	61	17.4
	Light	30	14.2	11	7.9	41	11.7
	Hot environment	14	6.6	1	0.7	15	4.3
	Medical and nursing interventions during sleep hours]	19	9.0	14	10.1	33	9.4
	Unfamiliar environment	50	23.6	23	16.5	73	20.8
	Worries about the disease	19	9.0	33	23.7	52	14.8
	The patient's waking up often	33	15.6	41	29.5	74	21.1
	Other	1	0.5	1	0.7	2	0.6

The comparison between the study and control groups' PSQI and PFS is shown in Table 3. A statistically significant difference was found between PSQI and PFS median scores of the study and control group patient relatives. It was found that relatives of patients who received care and treatment in internal and surgical medicine clinics had higher PSQI and PFS median scores (Table 3).

Table 3. Comparison of study and control group patient relatives' PSQI and PFS scores

	Control group	Study group	Test value	p value
PSQI	10 (2–16)	8 (0–16)	2.568.50	0.041
Component 1 (subjective sleep quality)	2 (0–3)	2 (0–3)		
Component 2 (sleep latency)	2 (0–3)	2 (0–3)		
Component 3 (sleep duration)	2 (0–3)	2 (0–3)		
Component 4 (habitual sleep efficiency)	2 (0–3)	0 (0–3)		
Component 5 (sleep disturbances)	1 (0–1)	1 (0–2)		
Component 6 (sleep medication use)	0 (0–3)	0 (0–3)		
Component 7 (daytime dysfunction)	1.5 (0–3)	2 (0–3)		
PFS	6.09 (2–9)	4.95 (1–9)	2278.0	0.002

Behavioural factor	6.42 (2–9)	4.83 (1–9)
Affective factor	6.20 (2–9)	5 (1–9)
Sensory factor	6.5 (1–9)	5.20 (1–10)
Cognitive factor	5.5 (1–9)	5 (1–9)

U: Mann–Whitney U test statistic.

The relationship between PSQI and PFS is shown in Table 4. A positive moderate relationship was found between PSQI and PFS total scores ($r = 0.575$, $p < 0.05$) (Table 4).

Table 4. The relationship between PSQI and PFS

	PFS
PSQI	0.575*

Spearman’s correlation coefficient. * $p < 0.05$

4. Discussion

The results obtained in this study, which was conducted to find out the relationship between sleep quality and fatigue levels in relatives of patient hospitalised in the palliative care unit of a hospital in Central Black Sea region in the north of Turkey, are discussed in line with the related literature.

In this study, there was a statistically significant difference between the study group and control group median PSQI total scores and it was found that sleep quality of patient relatives in the control group was worse when compared with the study group. When studies conducted were examined, in a study conducted by Yilmaz and Sari [23] on the relationship between sleep quality and fatigue levels of relatives of patients with chronic disease, the PSQI total score of patient relatives was found as 6.68 ± 2.39 , while was found as 9.16 ± 3.33 in Yildirim’s [24] study. In a study in which Karabulutlu et al. [25] examined the sleep quality and psychological problems of caregivers of cancer patients, the PSQI total score of care givers was reported as 9.87 ± 3.95 . In Gorgulu and Akdemir’s [12] study, the PSQI total score of caregivers of cancer patients was found as 10.10 ± 3.16 in the first chemotherapy cycle and as 7.70 ± 3.56 in the sixth cycle. It is reported in the literature that together with training/counselling service given to patient relatives providing care, cognitive and behavioural interventions applied to individuals with sleep problem affect sleep quality positively [12], [26]. The reason why sleep quality of relatives of patients getting treatment in palliative care is better when compared with relatives of patients getting treatment in other units may be associated with the fact that families are involved in care starting from the first moment in line with the philosophy of palliative care and holistic nursing care.

In this study, the PFS median score was found as 6.09 (2–9) in control group of patient relatives ($p < 0.05$). The PFS total mean score was found as 4.40 ± 0.98 in Yilmaz and Sari’s [23] study on caregivers, while it was found as 4.4 ± 2.4 in a study in which Yildizeli [27] examined the fatigue levels and coping attitudes in caregivers of geriatric cancer patients; it was found as 5.33 ± 2.30 in the first chemotherapy cycle and as 4.08 ± 2.26 in the sixth cycle in a study by Gorgulu and Akdemir [12] on caregivers of cancer patients. It is reported in the literature that patient relatives experience various levels of fatigue [6], [7], [18], [25], [28]–[31]. In cases when the patient cannot provide symptom control at home, palliative care clinics provide the required care environment for patients and their relatives. In this case, palliative care is provided with an interdisciplinary care to meet the needs of both patients and patient relatives. It is reported in the literature that patients who receive palliative care have better symptom control and they have increased psychological well-being [32], [33]. It is thought that this may be effective in lower fatigue levels of patient relatives who receive treatment in palliative care clinics.

In this study, a statistically significant difference was found between the PSQI and PFS total median scores of study and control group patient relatives ($r = 0.575$, $p < 0.05$). It was found that fatigue levels

of patient relatives increased as their sleep quality decreased. Sleep is a basic physiological need for individuals to be able to participate in their activities during the day and to fulfil their roles and responsibilities properly. Changes that occur in the sleep structure of individuals lead to a decrease in sleep quality and may cause individuals to feel more tired and exhausted [34], [35]. At the same time, individuals who experience fatigue during the day may have problems that affect their quality of life such as sleep disorders, decreased sleep quality and anxiety [36]. Our study results are thus parallel with the literature.

In the caregiving process, patient relatives try to balance their own needs and their responsibilities towards the individual they provide care for [37]. When there is no balance, physical problems such as deterioration in sleep quality and fatigue may develop in addition to psychological problems such as anxiety and depression in patient relatives [38]. For this reason, nurses should plan, implement and evaluate nursing care periodically with a holistic and humanistic perspective to meet the needs of patients in addition to patient relatives and they should provide training and counselling parallel with the needs of patients and relatives [12], [23], [25].

5. Conclusion

In this study, a statistically significant difference was found between PSQI and PFS total median scores of study and control group patient relatives. A positive moderate correlation was found between PSQI total score and PFS total score. In line with the results obtained in the study, it is recommended to:

- find out the problems, especially sleep problems and fatigue, experienced by patient relatives and to evaluate these regularly;
- plan and implement interventions to increase the sleep quality and fatigue levels of patient relatives;
- find out the other factors that may affect the fatigue and sleep problems of patient relatives and to provide individualised and holistic nursing care.

Conflict of interest

The authors have no conflicts of interests to disclose.

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