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# Research Article Evaluation of sleep quality, anxiety and depression levels in mothers of children with cancer



Kanserli çocukların annelerinde uyku kalitesi, anksiyete ve depresyon düzeylerinin değerlendirilmesi



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### ABSTRACT

**Introduction**: Malignant and chronic diseases in children affect all family members economically and psychologically and can cause serious adjustment problems and psychological disorders. This study is aimed to compare the depression/anxiety levels and sleep quality of mothers who had children with and without cancer diagnosis.

**Methods:** Case group consisted of mothers of the children who applied to the Pediatric Hematology-Oncology Service and Polyclinic and diagnosed with cancer. Control group consisted of mothers of healthy children. The Pittsburg Sleep Quality Index (PSQI), Hospital Anxiety and Depression Scale (HADS) were used to the mothers.

**Results:** In the mothers of children with cancer; anxiety was found as 47.1% and depression was detected as 84.1% (p<0.001). There was a sleep disorder in 32.9 % (n=56) of the mothers of children with cancer (p=0.007). It was observed that 58.9% (n=53) of the mothers with sleep disorder had anxiety and 74.4% (n=67) of them had depression. There was a statistically significant relationship between sleep quality and anxiety and depression (p<0.001). Compared to the control group, the anxiety frequency of mothers of children with cancer increased 9.185 times [OR=9.185, 95% Cl (4.993-16.898); and depression frequency increased 23.748 times [OR=23.748, 95% Cl (13.480-41.837)].

**Conclusions:** In this study, it was determined that the anxiety and depression levels of mothers of cancer children were higher than those of mothers without cancer and the sleep quality was worse. Education and counseling services to be given to the mothers will be effective in decreasing anxiety and depression levels and increasing sleep qualities and reducing fatigue.

Keywords: Child, Neoplasms, mother, anxiety, depression, sleep wake disorders

## ÖZ

**Giriş:** Çocuklardaki malign ve kronik hastalıklar tüm aile üyelerini ekonomik ve psikolojik olarak etkilemekte ve ciddi uyum problemlerine ve psikolojik bozukluklara neden olabilmektedir. Bu çalışmada, kanser tanısı olan ve olmayan çocukların annelerinde depresyon / anksiyete düzeyleri ile uyku kalitelerinin karşılaştırılması amaçlanmıştır.

Yöntem: Vaka grubu, Pediatrik Hematoloji-Onkoloji Servisi ve Polikliniğine başvuran ve kanser tanısı alan çocukların annelerinden oluşuyordu. Kontrol grubu sağlıklı çocukların annelerinden oluşuyordu. Annelere Pittsburg Uyku Kalitesi İndeksi (PSQI), Hastane Anksiyete ve Depresyon Ölçeği (HADS) uygulandı.

**Bulgular:** Kanserli çocukların annelerinde; anksiyete % 47,1, depresyon % 84,1 olarak tespit edildi (p <0,001). Kanserli çocukların annelerinin % 32,9'unda (n=56) uyku bozukluğu mevcuttu (p=0,007). Uyku bozukluğu olan annelerin % 58,9'unun (n=53) anksiyete, % 74,4'ünün (n=67) depresyon geçirdiği görülmüştür. Uyku kalitesi ile anksiyete ve depresyon arasında istatistiksel olarak anlamlı bir ilişki vardı (p <0,001). Kontrol grubu ile karşılaştırıldığında kanserli çocukların annelerinin kaygı sıklığı 9,185 kat [OR = 9,185, % 95 Cl (4,993-16,898) ve depresyon sıklığı 23,748 kat artmıştır [OR = 23,748, % 95 Cl (13,480-41,837)].

**Sonuç:** Bu çalışmada kanserli çocukların annelerinin anksiyete ve depresyon düzeylerinin sağlıklı çocukların annelerine göre daha yüksek olduğu ve uyku kalitesinin daha kötü olduğu belirlenmiştir. Annelere verilecek eğitim ve danışmanlık hizmetlerinin; kaygı ve depresyon düzeylerini azaltmada, uyku kalitesini arttırmada ve yorgunluğu azaltmada etkili olacağını düşünmekteyiz. **Anahtar Kelimeler:** Çocuk, kanser, anne, kaygı, depresyon, uyku bozuklukları

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#### Introduction

Malignant and other important chronic diseases in children affect all family members economically and spiritually and may cause severe adjustment problems and psychological disorders [1]. Mothers and fathers are usually responsible for the child with chronic illness [2]. Parents who try to cope with treatment burden of the child increasing day by day, as well as the side effects of the cancer treatment, are often postponing their needs because they completely focus on the needs of their ill child. As the disease gets worse, care burden of the disease may also increase [3]. Several studies have shown that cancer and chronic diseases lead to various psychological and physical problems in children and families [4,5].

Sleep disorder is often overlooked, although it is one of the most common problems in caregivers of cancer patients. Socio-demographic characteristics, lifestyle and environmental factors, mental factors such as anxiety and depression, as well as disease and treatment-related factors, may be effective in the development of sleep disorders in the mothers of cancer children. When studies are examined, it is seen that the majority of parents are experiencing sleep disorders as a result of the mental stress resulting from the care of the child [6-8]. Many studies have shown that there is a relationship between mental health and sleep disorders [9,10]. In fact, the child's cancer causes sleep disturbances and the increase of anxiety in mothers.

Depression is the emotional reactions which occur in response to undesirable or disappointing life events in healthy people and involve distress, sadness, and grief; and it can be regarded as a normal part of life [7]. Anxiety is a reaction to the individual's destructive, destructive situations towards his being. There is uneasiness, anxious face, nervousness, sudden irritation, sudden anger, impatience and restlessness in the patient. Sleep problems can also be caused by mood disorders such as anxiety and depression [11,12].

In a large part of parents, insomnia is accompanied by anxiety and depression problems. It is seen in the studies that sleep disorder is an important determinant of depression in caregivers [7].

This study is intended to compare compare the socio-demographic characteristics, depression / anxiety levels and sleep quality of mothers of children with and without cancer.

#### Methods

#### The type and the place of the study

This case-control analytical study was performed between the dates of 18.09.2014-27.02.2015. Case group consisted of mothers of 170 children diagnosed with cancer who applied to Hematology-Oncology Service and Polyclinic; and control group consisted of mothers of healthy children without any chronic illnesses who applied to the pediactric polyclinic of the same hospital. The individuals in both groups were similar in terms of age and marital status. The socio-demographic questionnaire, Pittsburg Sleep Quality Index (PSQI), Hospital Anxiety and Depression Scale (HADS), which were formed in accordance with the sources, were applied to the mothers. The survey questions were administered by face to face interview technique. The number of subjects to be taken into the study was calculated using the formula  $n=t^2$ .p.  $q/d^2$  since the number of the individuals in the universe was not known. When the incidence of sleep quality disorder was accepted as 88.7% in patients' relatives, it was planned to take at least 163 cancer patients' mothers in this study according to this account.

#### Ethical Authorisation of the study

Before the study was started, an ethical approval numbered 2014/682 was received from Necmettin Erbakan University, Meram Medical Faculty, Ethics Committee for Non-Interventional Studies on the date of 20.06.2014. Oral and written approvals were obtained by giving information about the illness to the patients. Those with chronic illnesses, mothers with babies under the age of one year, those who were not intellectual enough to fill in the questionnaire, those who refused to participate in the study, and those who were currently on psychiatric treatment were not included in the study.

#### Collecting the data

#### Evaluation of sociodemographic characteristics

The sociodemographic characteristics of the mothers were questioned with the aim of collecting the necessary data for the research. The ages, educational status, occupations, marital status, monthly income of the mothers and their husbands' educations and jobs; where and in what type of place they live, number of children, number of the rooms at home, number of the people at home, the age and gender of the cancer child; for how many years the child was diagnosed with cancer, how often he/she applied to emergency service due to cancer, whether the father was interested in the child enough for the disease, whether the mothers smoked or not, whether there were smokers at home and whether the mother had any diagnosed illnesses were all recorded.

#### **Pittsburgh Sleep Quality Index**

Pittsburgh Sleep Quality Index (PSQI) was developed by Buysse et al. and it is a self-report based screening and assessment test that provides detailed information about sleep quality and type, and severity of sleep disorder in the last one month [13]. The index consists of 24 questions in total and the scores related to 7 components are obtained. These include subjective sleep quality, the period to fall asleep, sleep duration, usual sleep activity, sleep disorder, usage of sleep pill and daytime dysfunction. Last 5 questions are replied by husband or a roommate. These 5 questions are used for clinical information only and not evaluated. Each question is evaluated with a number from 0 to 3. The total scores of 7 components give total PSQI score. The total PSQI score can range from 0-21. The sleep quality of those with a total score of 5 or less is evaluated as 'good'; but if it is above 5, it is considered to be bad. The Turkish validity and reliability study of this index was performed by Ağargün et al [14].

#### Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) was used to determine the anxiety and depression status of the patients. HADS is a self rating scale developed by Zigmoid and Snaith (1983) to determine the risk for anxiety and depression and to measure the level and the change of violence. The purpose of the scale is not to diagnose but to determine the risk group by scanning anxiety and depression in those who have physical illnesses in a short time. Seven of the questions in the scale investigates depression, and 7 answers anxiety symptoms. A total of 14 questions are included and odd numbers measure anxiety and even numbers measure depression. The responses are rated in 4-point likert and scored between 0 and 3. There are Anxiety (HAD-A) and depression (HAD-D) subscales. As a result of a study in Turkey, cut-off score for anxiety subscale was found to be 10/11, and for the depression subscale it was found to be 7/8. Accordingly, those above these scores are considered at risk. The lowest score that patients can take from both subscales is 0, the highest score is 21[15,16].

#### Statistical analysis

Coding and statistical analysis of the data were performed on the computer in the SPSS (SPSS Inc., Chicago, IL, USA) 20.0 package program. Frequency, mean, standard deviation, median, minimum and maximum values, Odds ratios were calculated. The Mann-Whitney U test was used for comparison of the organs, and the Chi-square test was used for the comparison of qualitative data since the distributions of the data were not normal. The results were evaluated in confidence interval of 95.0%, and the significance was evaluated at p < 0.05 level. Pearson correlation analysis was used to calculate correlations. Correlation coefficient (r) was evaluated as weak between 0.00–0.24, moderate between 0.25-0.49, strong between 0.50-0.74, very strong relation between 0.75-1.00. The significance level was accepted as p < 0.05.

#### **Results**

Case group consisted of mothers of 170 children with cancer who were followed up at Pediatric Hematology-Oncology Service and Polyclinic; and control group consisted of mothers of 170 healthy children who applied to the pediatric polyclinic of the same hospital without a cancer diagnosis.

There was no statistically significant difference between marital status (p=0.698) of mothers of children with and without cancer and between professional status of their husbands (p=0.158). When the educational levels of the mothers were compared, it was seen that the mothers of the children with cancer were less educated. The difference between them was statistically significant ( $x^2$ =35.688, p<0.001). The cancer incidence in children of mothers with primary or less education was 3.845 times higher than those with secondary or more education [OR:3.845,95%CI (2.451-6.033)]. Cancer in children of working mothers was less common than in those who did not work. The difference between them was statistically significant ( $x^2$ =22.187, p<0.001). The incidence of cancer in the children of non-working mothers increased by 3.576 times compared to working mothers [OR:3.576,95%CI (2.067-6.185)]. When comparing the residential areas, it was seen that those who had children with cancer mostly lived in the towns and villages, while the others lived in the city center. This was statistically significant ( $x^2$ =29.472, p<0.001). (Table 1). When we look at the level of education of husbands, it is seen that the majority of the fathers in the case group had primary or less education, however, most of the fathers in the control group had secondary or more education ( $x^2$ =24.968, p<0.001) (Table 1). The incidence of cancer in the children of the set with secondary and upper education [OR:3.357,95%CI (2.065-5.455)].

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	Case group		Control group		Total		•	
	n	%	n	%	n	%	$\chi^2$	P*
Education level								
≤Primary school	117	65.4	62	34.6	179	100.0		
educated							35.688	<0.001
≥Secondary school	53	32.9	108	67.1	161	100.0		
educated								
Employment status								
Employed	22	27.2	59	72.8	81	100.0		
Unemployed	148	57.1	111	42.9	259	100.0	22.187	<0.001
Marital status								
Married	157	50.5	154	49.5	311	100.0		
Single	13	44.8	16	55.2	29	100.0	0.151	0.698
Partner' s education								
≤Primary school	76	69.7	33	30.3	109	100.0		
educated							24.968	<0.001
≥Secondary school	94	40.7	137	59.3	231	100.0		
educated								
Partner's employment s	tatus							
Employed	24	62.2	14	37.8	38	100.0		
Unemployed	146	48.3	156	51.7	302	100.0	1.995	0.158
Residental area								
Urban	107	41.6	150	58.4	257	100.0		
Rural	63	75.9	20	24.1	83	100.0	29.472	<0.001

Table 1. Sociodemographic characteristics of case and control group

\* chi-square test

A comparison of the median age, anxiety, depression, and PSQI data of the case and control groups is shown in Table 2.

	Case group Median (Min-Max)	Control group Median (Min-Max)	Z	p**
Mother's age (year)	36.0 (23-54)	37.0 (20-54)	-0.765	0.444
Child's age (year)	7.5 (0-19)	7.5 (0-18)	-1.496	0.135
Anxiety	10.0 (0-20)	4.5 (0-18)	-10.387	< 0.001
Depression	11.0 (2-19)	3.0 (0-17)	-12.787	< 0.001
PSQI score*	4.0 (0-16)	3.0 (0-13)	-3.754	<0.001

Table 2. Comparison of age, anxiety, depression and PSQI scores

\*Pittsburg Sleep Quality Index \*\* One-Way ANOVA

Depression was detected in 84.1% (n=143) of the mothers of the children with cancer but it was in the rate of 18.2% (n = 31) of the mothers of healthy children. Depression was more common in mothers of children with cancer than mothers of children without cancer. The difference between them was statistically significant ( $x^2$ =147.658, p<0.001) (Table 3). The incidence of depression in mothers of children with cancer increased 23.748 times compared to the mothers of children without cancer [OR=23.748, 95%CI (13.480-41.837)].

#### Table 3. Comparison of depression, anxiety and sleep quality in case and control groups

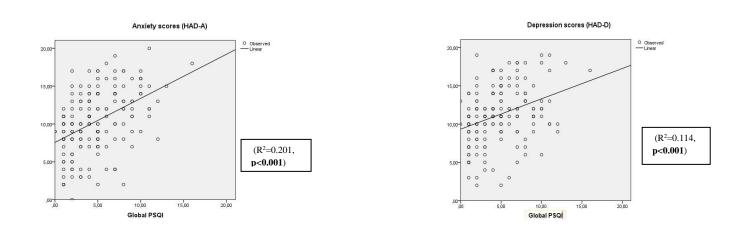
	Case Group		Control Group			
	n	%	n	%	$\chi^2$	p**
Depression status						
Non depressive HAD-D* score <8	27	15.9	139	81.8		
Depressive HAD-D score ≥8	143	84.1	31	18.2	147.658	< 0.001
Anxiety status						
No anxiety HAD-A score<11	90	52.9	155	91.2		
Anxiety HAD-A score ≥11	80	4.1	15	8.8	61.719	< 0.001
PSQI*						
PSQI ≤5 scores Good sleep quality	114	67.1	136	80.0		
PSQI >5 scores Poor sleep quality	56	32.9	34	20.0	7.314	0.007

\*Pittsburg Sleep Quality Index \*\* chi-square test \*HAD-D: Hospital Depression Scale \* HAD-A: Hospital Anxiety Scale

Anxiety was found in 47.1% (n = 80) of the mothers of cancer children, while 8.8% (n = 15) of the mothers of healthy children had anxiety. Anxiety was more prevalent in mothers of children with cancer than in mothers of children without cancer. A The difference between them was statistically significant ( $\chi^2$ =61.719, p<0.001) (Table 3). The anxiety frequency of mothers of children with cancer was 9.185 times higher than the control group [OR:9.185, 95%Cl (4.993-16.898)].

32.9% (n=56) of the mothers of the children with cancer had poor sleep quality, while it was detected in the rate of 20.0 % (n=34) in mothers of children without cancer (Table 3). The difference between them was statistically significant ( $\chi^2$ =7.314, p=0.007). The sleep quality of mothers of cancer children was 1.965 times worse than the sleep quality of mothers of children without cancer [OR:1.965, 95% CI (1.2-3.219)].

The scores of anxiety, depression and the correlations of sleep quality of the participants are seen in Table 4.



Graph 1. Linear regression analysis between anxiety scores and global PSQI scores in case group

Graph 2. Linear regression analysis between depression scores and global PSQI scores in case group

There was a positive moderate correlation between PSQI scores and anxiety scores of the mothers with cancer children (r=0.448, p<0.001). When linear regression analysis is performed, 20.1% of the height in the anxiety score is attributed to the increase in global PSQI scores ( $R^2$ =0.201, p<0.001) (Graphic 1).

There was a positive moderate correlation between global PSQI scores and depression scores of the participants (r=0.337, p<0.001). When linear regression analysis is performed, 11.4% of the height in the depression score is attributed to the increase in global PUKI score (R<sup>2</sup>=0.114, p<0.001) (Graphic 2).

		1	2	3	4	5	6	7	8	9
1.Depression score	r									
	р	1								
2.Anxiety score	r	0.706**	1							
	р	<0.001	1							
3.Subjective sleep quality	r	0.268**	0.369**	1						
	р	<0.001	<0.001	1						
4 Sleen latenay	r	0.144	0.234**	0.285**	1					
4.Sleep latency	р	0.060	0.002	<0.001	1					
5.Sleep time	r	0.211**	0.270**	0.255**	0.345**	1				
5.Steep tille	р	0.006	<0.001	0.001	<0.001	1				
6.Habitual sleep activity	r	0.031	0.138	0.201	0.485	0.352	1			
0.Habitual sleep activity	р	0.685	0.074	0.009	<0.001	<0.001	1	1		
7.Sleeping disorder	r	0.254**	0.250	0.162**	0.174	0.239	0.052	1		
7.steeping disorder	р	<0.001	0.001	0.035	0.023	0.002	0.504	1		
8.Using sleeping pill	r	-0.005	-0.250**	-0.050	0.078	0.156	-0.032	-0.001	1	
	р	-0.952	0.743	0.518	0.314	0.042	0.678	0.989	1	
9. Daytime dysfunction	r	0.268**	0.369	0.551**	0.285**	0.255**	0.201**	0.162*	-0.050	1
*Completion is immediate	Р	<0.001	<0.001	<0.001	<0.001	0.001	0.009	0.035	0.518	1

Table 4. Correlation of anxiety, depression scores and sleep quality of participants

\*Correlation is important at 0.05 level. \*\* Correlation is important at 0.01 level.

#### Discussion

The disease is a sudden development for the family as well as for the individual, and all family members are affected by this new situation. For this reason, compliance with this situation occurs after the situation emerges. Taking care of an individual with a chronic or acute illness, meeting his/her needs and helping him/her can bring about physical, psychological, social and economic problems for his family and relatives [3,17]. In this study, as well as examining socio-demographic characteristics of mothers of children diagnosed with cancer, the relationship between depression-anxiety levels and sleep quality of mothers with and without cancer was investigated.

It is seen in our study that the education level of the mothers was low. 65.4% (n =117) of the mothers of children with cancer had primary and lower education; 32.9% (n=53) of them had secondary and upper education. According to TNS A-2013 data, 22.0% of women aged 45-49 in Turkey had no education or did not finish primary school. However, this rate falls to 13% among women in the 25-29 age group. 69.0% of women in the 15-19 age group have a secondary education level [18]. The fact that the parents' education levels of ill children are lower than healthy controlllers may be a variable which affects the data of our study. The educational level of the mothers is of great importance both for their own health and the health status of their children. The low level of education plays an important role in the anxiety and depression levels of ill children and their mothers in relation to the lack of information about the illness, misconduct, and the inability to solve the problem. Quine and Pahl argue that having a higher education can reduce the negative effects of having a child with chronic illness and that mothers can have analytical thinking and problem-solving skills to reach more information and to create more positive coping strategies [19].

In our study, depression and anxiety scores of mothers with cancer children were higher than the mothers of children without cancer. Anxiety was found in 47.1% (n = 80) of the mothers of cancer children while this rate was 8.8 % (n=15) in mothers of children without cancer. Depression was detected in 84.1% (n=143) of the mothers of children with cancer but 18.2% (n=31) of the mothers of children without cancer, had depression. The incidence of depression in the mothers of children with cancer was 23.748 times higher than the mothers of children without cancer, and the anxiety incidence was 9.185 times higher as well. Malignancies and important chronic diseases in children affect all individuals of the family economically and psychologically and may cause serious adjustment problems and mental disorders [1]. Some studies have shown that there are various psychological and physical problems in children and in their families [4,5]. In a survey conducted with the families of children with cancer, it was reported that the mothers were affected by this situation most and the presence of psychological problems of mothers was also frequently expressed by researchers, clinicians, and mothers themselves [20]. Other studies indicate that family members are affected by a chronic illness in

the family, especially mothers; and anxiety and depression are diagnosed more in those families, the families need both financial and psychological support [20,23].

The prevalence of depression in the mothers of cancer children was 23.748 times higher than the mothers of children without cancer. It was also seen there were different results in this regard. Ozguven and Unluoglu (1988) found that parents who had children with chronic illnesses did not have more psychiatric problems than parents with healthy children; although this group had more problems, there was not much difference between them. This small difference, by the way, can be attributed to their acceptance of the situation and to their belief that they themselves and their health care providers are doing everything that is appropriate for the treatment [24]. In our study, there was no relationship between mother's marital status, father's level of interest, working status and mother's anxiety. In our study, no relation was found between the socio-demographic characteristics of the mothers and their sleep quality. Anxiety findings were also associated with 58.9% of mothers with poor sleep quality. In the study conducted with parents, they stated that giving care had a negative effect on their physical and emotional health [25].

Studies show that the sleep quality of caregivers for cancer patients is bad [26]. The results of our study were similar to the literature, and the PSQI scores of caregivers were found to be worse. In our study, 74.4% of the mothers with poor sleep quality were accompanied by depression. There was a statistically significant relationship between sleep quality and depression. In our study, it was also seen that the sleep quality of mothers of children with cancer was worse than the control group. Sleep disturbances were found in 32.9% of the mothers of the children with cancer, and this incidence was found as 20.0% in the control group. It is reported that poor sleep quality of primary caregivers of cancer patients affect the life quality of the caregivers negatively as well because this can affect the physiological and psychological health of the individual and their interpersonal relationships [27]. Sleep quality is a concept related to physical and mental health. Sleep problems are therefore directly related to physical and psychological stress. The decrease in sleep quality is often seen in caregivers for cancer patients.<sup>27</sup> The results of our study were similar to the literature, and the PSQI scores of caregivers were found to be worse. In our study, there was no relationship between sleep quality and socio-demographic characteristics of mothers. In another study which examined the physical, psychological and social well-being of mothers of children with cancer, it was reported that sleep disorders were at high level in caregivers and they slept less due to children's care and their worries about cancer, they had difficulty in falling asleep and maintaining sleep [28]. These results were consistent with our study.

#### Limitations

Although the subject of our study was very broad and important, we had to keep our working group small. The fact that this study was not planned in larger groups as a multi-center study shows our limitation. In this study, it was our most important limitation that mothers were not investigated for disturbances such as sleep, depression and anxiety.

#### Conclusion

Beginning from the cancer diagnosis, it is advised to evaluate the anxiety and depression of the patients and the relatives during and after the treatment. Both the patients and their mothers should be helped to express their problems. It is thought that directing the caregiver mothers to the people and institutions where they can get help when needed will also positively affect the child's treatment process.

We are thinking that education and counseling services to mothers will be effective in decreasing anxiety and depression levels, improving sleep quality and reducing fatigue.

Informing the family about the disease process and giving psychological support in this regard will help them cope more easily with stress, so the adaptation process to the disease will be more easily overcome. Thus, the physical, psychological and social well-being of the family can be prevented from being adversely affected.

It may be advisable for primary health care providers to consider the distresses of the families with cancer patients, to regularly determine the sleep quality, anxiety and depression levels of them and to prepare an holistic education plan for the problems.

Opening of the units that provide psychological support and providing counseling services will be effective in reducing the anxiety and depression levels, increasing the sleep quality and reducing fatigue of the relatives of cancer patients. Social support is important for caregivers' mental health. The findings of this study will guide the future researches.

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