



The predictive power of disease management of parents with children with cancer on fatigue and sleepiness levels

Aslı Akdeniz Kudubes¹ · Murat Bektas² · Dijle Ayar³ · İlknur Bektas^{2,4}

Accepted: 4 August 2023 / Published online: 14 August 2023

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Abstract

This study was conducted as a descriptive, correlational, and cross-sectional research to determine the predictive power of disease management of parents of children with cancer on fatigue and sleepiness levels. Study data were collected by using a Parent Information Form, the Chalder Fatigue Scale, the Epworth Sleepiness Scale, and the Family Management Measure. Mean scores, percentage calculations, Pearson correlation analysis, and linear regression analysis were used in the analysis of data. Three models were created according to the relationship between the variables in the multiple regression analysis. In Model 1, the first sub-dimension of the disease management scale explained 59.7% of the level of fatigue and sleepiness. In Model 2, the second sub-dimension of the disease management scale explained 69.4% of the level of fatigue and sleepiness. In Model 3, the third sub-dimension of the disease management scale explained 67.5% of the level of fatigue and sleepiness. Childhood cancer is a family disease that affects parents as well as children. This is an important study revealing the effect of chronic disease management on the fatigue and daytime sleepiness of parents with children with cancer. Considering the outcomes of this study, nurses should be aware of the possible effects of disease management on the level of fatigue and daytime sleepiness. Nurses should not forget that families who cannot manage chronic diseases effectively and successfully may have high levels of fatigue and sleepiness.

Keywords Disease management · Fatigue · Sleepiness · Cancer · Parent

Introduction

Cancer is seen as a family disease because it changes the lives of both the child and the family. Many physical and psychosocial differences occur in the lives of parents, depending on the course of the disease and the treatment process of the child following a diagnosis of cancer (Kim et al., 2019).

When their children are diagnosed with cancer, parents have difficulty in managing the disease due to physical, psychological, economic, and social difficulties (Santos et al., 2018). During this period, parents face a variety of problems on top of managing the disease. These include medical issues related to treatment and care and interactions with the team that maintains this care. Additionally, inadequate economic resources, childhood development and academic progress, family and relationship issues and future concerns are often reported (Piran et al., 2017; Santos et al., 2018).

When parents can manage the disease and cope with the difficulties they experience, the daily life of both the child and the family can continue normally. However,

✉ Aslı Akdeniz Kudubes
asliakdeniz@hotmail.com

Murat Bektas
mbekta@gmail.com

Dijle Ayar
dijle.ayar@alanya.edu.tr

İlknur Bektas
ilknurbektas23@gmail.com

¹ Department of Pediatric Nursing, Faculty of Health Sciences, Bilecik Şeyh Edebali University, Gülümbe, Bilecik, Turkey

² Department of Pediatric Nursing, Faculty of Nursing, Dokuz Eylül University, İnciraltı, İzmir, Turkey

³ Department of Pediatric Nursing, Faculty of Health Sciences, Alanya Alaaddin Keykubat University, Alanya, Antalya, Turkey

⁴ Department of Pediatric Nursing, Faculty of Health Sciences, İzmir Bakırçay University, Menemen, İzmir, Turkey

the difficulty of the disease management process causes some physiological and psychosocial problems in parents. Problems such as the presence of acute/chronic disorders, fatigue, sleep problems, and anxiety and depression can be particularly difficult to deal with during management of their child's cancer treatment (Katz et al., 2018; Shoghi et al., 2019).

Parents who have a child with cancer are affected by this process at least as much as the child. In this process, parents are faced with many physical problems, such as insomnia, fatigue, an increase in the incidence of infection, pain, and psychosocial problems, such as anxiety, depression, and burnout. Parents must both balance their own coping through this negative situation as well as take responsibility of supporting and caring for the child (Modanloo et al., 2019; Wang et al., 2019). Depending on this process, parents are faced with fatigue, sleep disorders, decreased quality of life, difficulty in providing care, and the emergence of various physiological and psychological diseases (van Schoors et al., 2018; van Warmerdam et al., 2019). One of the important problems that arise in parents during this period is fatigue. There is a relationship between fatigue and disease management. While the increase in the level of fatigue negatively affects the success of disease management, inadequate management of the disease process also increases the level of fatigue (Modanloo et al., 2019; Ozdemir Koyu & Tas Arslan, 2021; van Schoors et al., 2018). This situation makes it difficult for parents to get out of this cycle (Ozdemir Koyu & Tas Arslan, 2021). The fatigue experienced by parents can be physical and mental. Physical fatigue is expressed as physical tiredness, feeling weak, and weary. Mental fatigue, on the other hand, is characterized by a decrease in an individual's alertness and slowing down in cognitive functions, usually due to long-term mental activities or stress (Chuang et al., 2018; Engberg et al., 2017). Both types of fatigue are common in parents of children with cancer. Various problems, such as difficulty in caregiving, decrease in quality of life, anxiety, depression, daytime sleepiness, and sleep problems may occur in parents who experience fatigue (Halliday et al., 2017; Ozdemir Koyu & Tas Arslan, 2021).

Daytime sleepiness is a condition that causes various cognitive and psychosocial problems. It is the presence of an uncontrollable tendency to go to sleep when the individual's attention should be normal and awake. This is a different process from fatigue. Fatigue occurs after physical activities, and it does not cause one to go to sleep. Daytime sleepiness is caused by factors such as circadian rhythm disorders, gastroesophageal reflux, pain, noise, temperature differences, light condition, misuse of time, poor living conditions, illness and treatment processes, misuse of sleep time, inability to rest, and tiredness (He & Kapur, 2017).

Cancer diagnosis is a tiring process for caregivers, and the caregiver burden is quite high. Therefore, daytime sleepiness is a common condition in caregivers of patients with cancer (Keilty et al., 2018). Fatigue and daytime sleepiness can cause individuals to have difficulties in fulfilling daily activities. Parents play a major role in various issues, such as caring for a sick child, following medications, and managing symptoms. They may experience sleep problems due to difficulties that they experience while managing this process (Keilty et al., 2018).

It is very important to implement initiatives that will strengthen children with cancer and their families and make it easier for them to cope with this difficult disease process. In this way, the physical and psychosocial difficulties experienced by parents who are supported to manage this process healthily and effectively will be minimized. Unhealthy disease management negatively affects both the quality of life of parents and their own health (Piran et al., 2017). Fatigue and sleepiness are symptoms that are frequently affected by disease management, and determining the effect of disease management on these two symptoms will guide the planning of nursing interventions. When we look at studies on the effects of fatigue and daytime sleepiness of parents of children with cancer on disease management, most studies examine these three variables separately (Kim et al., 2019; Ozdemir Koyu & Tas Arslan, 2021; Piran et al., 2017) but that there are no studies showing the relationship between fatigue, sleepiness, and disease management.

This study seeks to determine the predictive power of disease management of parents of children with cancer on fatigue and daytime sleepiness, and the following research questions were raised for this aim:

1. What are the mean fatigue, daytime sleepiness, and disease management scores of parents of children with cancer?
2. What is the relationship between fatigue, daytime sleepiness, and disease management in parents of children with cancer?
3. What is the predictive power of disease management of parents of children with cancer on fatigue and daytime sleepiness?

Methods

Study design and participants

This descriptive, correlational, and cross-sectional study was conducted in the pediatric oncology-hematology clinic of a university hospital. The study consisted of participants (a) who were > 18 years old, (b) whose child was diagnosed

with cancer, (c) whose child was diagnosed with cancer at least one month ago, (d) who did not have psychiatric diagnosis and communication problems, and (e) who volunteered to participate in the study. Parents who did not volunteer to participate in the study and could not read and write Turkish were not included in the study. The minimum sample size required for the study was calculated by using the GPOWER 3.1 statistical analysis software, and the sample size required for multidimensional linear regression analysis was determined as 135 individuals, based on a significance level of 0.05, a power of 80%, and a medium effect size ($f^2=0.15$).

A total of 312 individuals were assessed for eligibility. However, individuals who had communication problems ($n=2$), whose child was diagnosed with cancer less than a month ago ($n=2$), and who refused to participate ($n=8$) were not included in the study. Therefore, parents of 300 children with cancer were included in the study by using the appropriate sampling method.

Outcome measures

The parent information form

This form consists of fourteen questions, the first eight of which are about the socio-demographic characteristics of children and their parents (age, gender, educational status, income status, and employment status). The remaining questions are about factors that indirectly affect the fatigue and sleepiness of the parents, such as the diagnosis of the child, the length of hospital stay, the duration of diagnosis, family type, number of children, and family support (Katz et al., 2018; Keilty et al., 2018; Modanloo et al., 2019; Ozdemir Koyu & Tas Arslan, 2021; Wang et al., 2019).

The Chalder fatigue scale (CFS)

This scale was developed by Trudie Chalder in 1993 and its Turkish validity and reliability study was conducted by Adin et al. in 2019. It is an easy, fast, practical, and self-report scale that is used to evaluate the fatigue felt by the individual during the last month (Chalder et al., 1993). The final version of the scale consists of a total of 11 items, including the 7-item physical fatigue subscale (CFS-PFS) and the 4-item mental fatigue subscale (CFS-MFS) (Cella & Chalder, 2010). The individual is asked to answer the statements on a four-point Likert-type scale (less than usual, as usual, more than usual, much more than usual). The total score ranges from 0 to 33, and high scores indicate high fatigue severity. Cronbach's alpha value of the total scale is 0.89 (Adin et al., 2019). The alpha value in this study was found as 0.88.

The Epworth Sleepiness Scale (ESS)

This scale is the most commonly used tool to measure sleepiness in sleep disorder studies. It is a simple, self-administered questionnaire developed by Johns (1992) and adapted into Turkish by Izci et al. (2008) (Izci et al., 2008; Johns, 1992). The participant is asked to rate the probability of falling asleep in eight different situations (scale items) during the previous month on a scale of 0–3 (0 = would never doze; 1 = slight chance of dozing; 2 = moderate chance of dozing; 3 = high chance of dozing). The total score of the scale ranges from 0 to 24, and people with high scores show more daytime sleepiness. Cronbach's alpha value of the scale is 0.86 (Izci et al., 2008). The alpha value in this study was found as 0.87.

The family management measure (FaMM)

This scale was developed by Knafl et al. (2011) and its Turkish validity and reliability study was conducted by Ergün et al. (2019) (Knafl et al., 2011). The Turkish version of the scale, which originally consists of 53 items and six sub-dimensions, has 42 items and three sub-dimensions. Each item on the scale is scored between 1 and 5. Items 3, 9, 10, 11, 14, 19, 24, 31, 32, 35, and 39 are reverse coded. A total score is not obtained from the scale; it is evaluated over sub-scale scores.

Sub-dimensions and number of questions

1. Disease management and the child's daily life (19 questions): Higher scores indicate a more normal life and that families find themselves more capable of disease management. This sub-scale includes items 1, 2, 3, 8, 10, 11, 12, 13, 14, 17, 18, 19, 24, 28, 30, 31, 32, 33, and 35.
2. Difficulties of life and incidence of the effects of the disease (16 items): Higher scores indicate that the condition is more serious and more difficulties are experienced. This sub-scale includes items 4, 5, 6, 7, 9, 15, 16, 20, 21, 22, 23, 25, 26, 27, 29, and 34.
3. Parental agreement (7 questions): High scores indicate that parents collaborate in the child's disease management. This sub-scale includes items 36, 37, 38, 39, 40, 41, and 42.

Cronbach's alpha coefficients of the first, second, and third sub-dimensions are 0.93, 0.87, and 0.84, respectively. Cronbach's alpha values in this study were found to be 0.91, 0.90, and 0.88, respectively (Ergun et al., 2019).

Data collection procedure

The participants were initially explained the purpose of the study and were asked to sign an informed consent form. Then the data were collected by the principal researcher. Data collection took approximately 15–20 min for each participant.

Table 1 Parents characteristics

		n	%
Age	20–29 years	88	29.3
	30–39 years	112	37.3
	40 years and over	100	33.4
Gender	Female	264	88.0
	Male	36	12.0
Education level	Elementary school graduate	110	36.6
	High school graduate	135	45.0
	University	55	18.4
Working status	Yes	59	19.7
	No	241	80.3
Reason for not working	Unpaid time off	70	29.1
	Report	35	14.5
	Resignation	15	6.2
	Housewife	121	50.2
Relationship with the child	Mother	264	88.0
	Father	36	12.0
Child age	0–6 years	106	35.3
	7–12 years	98	32.7
	13–18 years	96	32.0
Child gender	Girl	144	48.0
	Boy	156	52.0
Day of hospitalization	1–5 days	144	48.0
	6–10 days	102	34.0
	11 days and over	54	18.0
Economical status	Income less than expense	185	61.7
	Income equals expense	80	26.6
	Income more than expenses	35	11.7
Diagnosis of child	Acute Lymphoblastic Leukemia	82	27.3
	Acute Myeloid Leukemia	63	21.0
	Lymphoma	37	12.3
	Nervous system tumor	33	11.0
	Solid tumor	65	21.7
Time to diagnose	Other tumors	20	6.7
	1–4 months	115	38.3
	5–8 months	90	30.0
Family type	9 months and over	95	31.7
	Nuclear family	205	68.3
	Extended family	95	31.7
Total number of children	1–2	140	46.7
	3–4	110	36.7
	5 and over	50	16.6
Supported person presence	Wife/Husband	104	34.7
	Family	97	32.3
	Friend	51	17.0
	Clinical staff (Doctor, nurse, etc.)	48	16.0

Ethical considerations

At the outset, the permission of the owners of the scales used in the research was obtained via e-mail. Institutional permission was obtained to carry out the research. The study was approved by the Non-Interventional Clinical Research Ethics Committee of a university (Decision No: 5759-GOA, 2020/27–08). The principal researcher explained the purpose of the study and obtained verbal and written informed consent from all participants. Participants were allowed to withdraw from the study without giving any reason.

Data analysis

The data were analyzed by using the SPSS version 28.0 (IBM Corp). The Shapiro-Wilk-W test, histogram, and normal Q-Q plot were used for tests of normality. Frequency and percentage were calculated for categorical variables. Means and standard deviations were calculated for normally distributed features. The t-test and ANOVA test were used to examine the relationships between Parents characteristics and scale mean scores. The relationship between CFS and ESS and FaMM was evaluated by using Pearson correlation analysis, the predictive level of parents' disease management on fatigue and daytime sleepiness was evaluated by linear regression analysis, and the multicollinearity between fatigue and daytime sleepiness of parents and disease management was evaluated by VIF and tolerance analysis. A VIF value of < 10 , a tolerance value of < 0.2 , and a condition index value of < 15 , which are independent variables, were included in the regression analysis. Results were evaluated over a 95% confidence interval, and $p < 0.05$ was accepted as a level of significance.

Results

The sociodemographic and disease-related variables of the parents participating in the study are given in Table 1. We determined that parents participating in the study, were homogeneously distributed in terms of sociodemographic and disease-related variables ($p > 0.05$).

When the mean scores of parents in the study on CFS, ESS, and FaMM were examined, we found that the mean total score of CFS, the mean score of the physical fatigue, and mental fatigue sub-dimensions of CFS were 24.12 ± 6.28 , 12.75 ± 3.54 , and 11.37 ± 2.74 , respectively. The mean scores from the CFS show that most parents scored high for fatigue scale. The mean ESS score was found to be 18.66 ± 7.58 , suggesting most parents scored high for daytime sleepiness. We determined that the mean scores on the disease management and the child's daily life, difficulties

of life and the incidence of the effects of the disease, and parental agreement sub-dimensions were 48.68 ± 20.19 , 38.91 ± 20.12 , and 17.07 ± 9.80 , respectively. The mean scores from the FaMM sub-scales show that most parents scored high for family management measure scale.

Table 2 gives the results of Pearson correlation analysis about the relationship between mean CFS total and subscale scores, mean ESS total score, and mean FaMM subscale scores.

According to the relationship between the variables in the multiple regression analysis, the effect of the sub-dimensions of family management measure of parents of children with cancer on the level of fatigue and sleepiness was specified as three models. According to Model 1, the increase in disease management skills of parents of children with cancer is a significant predictor of fatigue and sleepiness ($p < 0.001$). According to the model, the first sub-dimension of the disease management scale explained 59.7% of the level of fatigue and sleepiness (Table 3). According to Model 2, the increase in the difficulties experienced by the parents of children with cancer in disease management is a significant predictor of the level of fatigue and sleepiness ($p < 0.001$). According to the model, the second sub-dimension of the disease management scale explained 69.4% of the level of fatigue and sleepiness (Table 3). According to Model 3, the increase in parental agreement in disease management of parents of children with cancer is a significant predictor of fatigue and sleepiness ($p < 0.001$). According to the model, the third sub-dimension of the disease management scale explained 67.5% of the level of fatigue and sleepiness (Table 3).

There was a statistically significant difference between the parents' age ($F = 4.510$; $p = 0.004$), education level ($F = 3.626$; $p = 0.013$), family type ($t = 2.707$; $p = 0.007$) and number of children ($F = 5.662$; $p = 0.001$) and the mean scores of FaMM, ESS and CFS. There was a statistically significant difference between the age of the child diagnosed with cancer ($F = 4.906$; $p = 0.004$), the child's diagnosis ($F = 3.560$; $p = 0.003$) and the number of days they stayed in the hospital ($F = 3.970$; $p = 0.008$) and the mean scores of FaMM, ESS and CFS.

As a result of the analyzes performed, variables (parent age, parent education level, family type, total number of children, child age, diagnosis of the child, day of hospitalization) that statistically affected the FaMM, ESS and CFS mean scores were included in the regression model. (Table 4). According to Model 1, increase in parental age, decrease in education level, being in a nuclear family structure, having three or more children, a child diagnosed with cancer in the 0–6 age group, a diagnosis of leukemia, hospitalization for more than 11 days, and illness of parents decrease in management abilities is a significant predictor of the increase in fatigue and sleepiness levels ($p < 0.001$, Table 4). According to Model 2, the increase in parental age, decrease in education level, being in a nuclear family structure, having three or more children, a child diagnosed with cancer in the 0–6 age group, a diagnosis of leukemia, hospitalization for more than 11 days, and children with cancer the increase in the difficulties experienced by the parents in the management of the disease is a significant predictor of the increase in the level of fatigue and sleepiness ($p < 0.001$; Table 4). According to Model 3, increase in parental age, decrease in education level, being in a nuclear family structure, having three or more children, a child diagnosed with cancer in the 0–6 age group, a diagnosis of leukemia, hospitalization for more than 11 days, and disease management decreased agreement between parents was a significant predictor of increased levels of fatigue and sleepiness ($p < 0.001$; Table 4).

Discussion

Childhood cancer is a health problem that reduces the quality of life by limiting the child and his family and causes some physical and psychological symptoms in parents depending on the caregiver burden and in which parents' success in disease management is important (van Schoors et al., 2018). This study was carried out to determine the predictive power of the disease management of parents of children with cancer on the level of their fatigue and sleepiness.

It was determined that most of the parents participating in the study had high CFS total and sub-dimension mean scores

Table 2 Correlation between variables

	1	2	3	4	5	6	7
1.FaMM First Sub-scale	1.000						
2.FaMM Second Sub-scale	-0.812	1.000					
3.FaMM Third Sub-scale	0.866	-0.916	1.000				
4.CFS Total Score	-0.911	0.862	-0.922	1.000			
5.CFS First Sub-scale	-0.908	0.879	-0.905	0.912	1.000		
6.CFS Second Sub-scale	-0.899	0.886	-0.914	0.918	0.920	1.000	
7.ESS	-0.879	0.925	-0.897	0.879	0.898	0.899	1.000

The Family Management Measure: FaMM; Chalder Fatigue Scale: CFS; The Epworth Sleepiness Scale: ESS; $p < 0.001$

Table 3 The level to which family management of parents predicted their fatigue and sleepiness level

Variable	Model 1				Model 2				Model 3						
	FaMM First Sub-scale				FaMM Second Sub-scale				FaMM Third Sub-scale						
	B	SE	β	t	p	B	SE	β	t	p	B	SE	β	t	p
CFS Total Score	-3.464	1.520	-0.193	-8.279	<0.001	0.686	0.064	0.547	10.281	<0.001	-0.663	0.161	-0.184	-4.113	<0.001
CFS First Sub-scale	-3.766	1.122	-0.184	-4.216	<0.001	0.606	0.296	0.381	4.049	<0.001	-0.669	-0.176	-0.299	-2.245	<0.001
CFS Second Sub-scale	-1.483	1.216	-0.289	-2.793	<0.001	0.606	0.296	0.381	4.049	<0.001	-0.492	0.242	-0.248	-2.035	<0.001
ESS	-2.483	0.822	-0.179	-2.862	<0.001	0.606	0.296	0.381	4.049	<0.001	-0.281	0.123	-0.261	-2.283	<0.001
R	0.654					0.679					0.699				
R ²	0.597					0.694					0.675				
F	592.235					657.627					688.378				
P	0.000					0.000					0.000				
Durbin Watson (1.5–2.5)	1.820					1.730					1.760				

B: Unstandardized Beta; SE: Standard Error; β : Standardized Beta; R: correlation; R²: correlation coefficient (explained variance ratio); F: model statistics; p: level of significance
 The Family Management Measure: FaMM; Chalder Fatigue Scale: CFS; The Epworth Sleepiness Scale: ESS

and ESS mean scores, and that most of the parents experienced excessive fatigue and daytime sleepiness. Diagnosis of cancer is a challenging process for both patients and their caregivers. Especially childhood cancers require parents to cope with many physical and psychosocial difficulties. During this period, while parents take care of their children, they also try to fulfill their other obligations of normal life (such as taking care of the other child, working life, maintaining order at home) (Hovén et al., 2017). In particular, cancer-specific situations, such as frequent hospitalizations, the intensity of the treatment plan, and the symptoms experienced by the child, are stated as factors that complicate the process experienced by parents. During this whole process, parents cannot find time to rest, spare time for themselves, and maintain their social lives (Hovén et al., 2017). This situation causes parents to experience both physical and mental fatigue and various sleep problems, such as difficulty falling asleep, frequent interruptions of night sleep, and shortening of sleep time. Accordingly, parents frequently experience daytime sleepiness (van Schoors et al., 2018). Similar to the literature, parents' fatigue and daytime sleepiness scale scores were found to be high in this study.

The collection of study data during the Covid-19 pandemic may have affected this study. The Covid-19 pandemic has become a process that negatively affects children with chronic diseases such as cancer and their parents both physically and psychosocially (Kotecha, 2020; Nerli et al., 2020.) In addition, reasons such as decreased social support for parents, increased home responsibilities, and having to stay at home to protect from infection due to the Covid-19 pandemic may have caused the mean score of fatigue and daytime sleepiness scale to be high.

The mean scores obtained from the FaMM scale sub-dimensions of this study show that parents do not find themselves competent for disease management and have difficulty. In addition, the majority of parents may not be able to continue the disease management of their children with their spouses. In particular, the fact that the needs of the child are mostly met by the mother and the mothers undertake all the disease management may cause this situation. Although the management of chronic diseases such as cancer is a challenging process, providing effective and sustainable disease management ensures that both the child and their parents experience the process more comfortably. The success of disease management reduces hospitalizations, decreases the negative physiological and psychological effects on parents, and increases the quality of life (Ergun et al., 2019). However, when the disease process is not managed effectively and sustainably, it causes negative consequences (increase in symptom burden, decrease in quality of life, anxiety, depression) for children and their parents (van Schoors et al., 2018). In this study, it is thought that parents'

Table 4 The level to which parents characteristics and family management of parents predicted their fatigue and sleepiness level

Variable	Model 1						Model 2						Model 3					
	FaMM First Sub-scale			FaMM Second Sub-scale			FaMM Third Sub-scale			FaMM First Sub-scale			FaMM Second Sub-scale			FaMM Third Sub-scale		
	B	SE	β	t	p	F	B	SE	β	t	p	F	B	SE	β	t	p	
Parent age ^a	-2.363	1.310	-0.182	-6.729	<0.001	0.866	0.044	0.457	8.822	<0.001	-0.466	0.116	-0.148	-3.218	<0.001			
Parent education level ^b	-1.667	1.212	-0.148	-3.162	<0.001	0.416	0.629	0.481	4.490	<0.001	-0.329	-0.167	-0.286	-2.234	<0.001			
Family type ^c	-1.283	1.416	-0.529	-1.789	<0.001	0.326	0.294	0.365	3.847	<0.001	-0.289	0.265	-0.342	-1.435	<0.001			
Total number of children ^d	-2.248	0.622	-0.159	-2.628	<0.001	0.509	0.962	0.321	4.159	<0.001	-0.251	0.154	-0.252	-2.323	<0.001			
Child age ^e	-1.323	1.250	-0.163	-5.279	<0.001	0.524	0.084	0.565	6.289	<0.001	-0.763	0.175	-0.143	-2.214	<0.001			
Diagnosis of the child ^f	-1.716	0.432	-0.134	-4.436	<0.001	0.763	0.356	0.367	3.069	<0.001	-0.687	-0.184	-0.254	-1.213	<0.001			
Day of hospitalization ^g	-2.413	0.816	-0.246	-1.733	<0.001	0.456	0.194	0.541	3.065	<0.001	-0.652	0.282	-0.346	-1.015	<0.001			
CFS Total Score	-3.464	1.520	-0.193	-7.279	<0.001	0.686	0.064	0.547	10.281	<0.001	-0.663	0.161	-0.184	-4.113	<0.001			
CFS First Sub-scale	-3.766	1.122	-0.184	-4.216	<0.001	0.606	0.296	0.381	4.049	<0.001	-0.669	-0.176	-0.299	-2.245	<0.001			
CFS Second Sub-scale	-1.483	1.216	-0.289	-2.793	<0.001	0.606	0.296	0.381	4.049	<0.001	-0.492	0.242	-0.248	-2.035	<0.001			
ESS	-2.483	0.822	-0.179	-2.862	<0.001	0.606	0.296	0.381	4.049	<0.001	-0.281	0.123	-0.261	-2.283	<0.001			
R	0.698					0.709					0.719							
R ²	0.682					0.752					0.745							
F	692.264					567.762					788.178							
P	0.000					0.000					0.000							
Durbin Watson (1.5–2.5)	1.620					1.630					1.660							

B: Unstandardized Beta; SE: Standard Error; β : Standardized Beta; R: correlation; R2: correlation coefficient (explained variance ratio); F: model statistics; p: level of significance

The Family Management Measure: FaMM; Chalder Fatigue Scale: CFS; The Epworth Sleepiness Scale: ESS

aWhite coding, the 40 years and over aged was coded as 1 and the 20–39 years aged was coded as 0; bWhite coding, the elementary school graduate was coded as 1 and the high school and university graduate were coded as 0; cWhite coding, the nuclear family was coded as 1 and the extended family were coded as 0; dWhite coding, the 3–4 and 5 child over were coded as 1 and the 1–2 child was coded as 0; eWhite coding, the 0–6 aged was coded as 1 and the 7–12 aged and 13–18 aged were coded as 0; fWhite coding, the Acute Lymphoblastic Leukemia and Acute Myeloid Leukemia were coded as 1 and the other diagnosis were coded as 0; gWhite coding, the 11 days and over was coded as 1 and the 1–5days and 6–10 days were coded as 0

low mean scores from the first and third sub-dimensions of the disease management scale and the high mean scores from the second sub-dimension may have been affected by many factors. For example, factors such as the child's age, diagnosis, social support, treatment plan, child's prognosis, parent's level of coping, peer-to-peer communication, the symptoms experienced by the child, and the physical and psychosocial problems experienced by the parent, may have played a role (Nursyamsiyah, 2019; Salvador et al., 2019). In addition, it is thought that parents may have had problems in managing the disease due to reasons such as decreased interpersonal interaction and decreased social support during the Covid-19 pandemic process.

The findings show that the disease management status of the parents of children with cancer was an important predictor of the level of their fatigue and sleepiness (Table 3). It was determined that as the ability of the parents to manage the disease decreased, the level of fatigue and daytime sleepiness increased. Parents' coping skills, self-confidence, finding themselves competent in taking care of the child, finding their ability to manage the child's disease adequate, and their cooperation in this process are important steps in reducing their level of fatigue and sleepiness (Salvador et al., 2019). There are many studies in the literature indicating that spousal support is beneficial for parents and that it has a positive relationship with the degree of adaptation to the child's disease process and management (Pietnoczko & Steuden, 2020; Shahriari et al., 2016). The quality of life of parents who can manage the disease process smoothly and adequately increases. This situation causes parents to experience fewer physical and psychological symptoms, thus reducing difficulties that they experience while giving care (Ergun et al., 2019). Thus, it is thought that parents with successful disease management feel less tired and that their sleepiness increases due to increased sleep quality. Apart from this, parents may encounter many problems while managing the disease and treatment process of their child diagnosed with cancer (Dalton et al., 2019; Ellis et al., 2017). For example, some of these problems include increase in the symptoms experienced by the child, frequent hospitalizations, financial difficulties, continuation of the treatment of the child in a city different from the city of residence, the presence of other dependent children, aggressive treatment protocols, increase in the frequency of visits to the hospital to check the health status of the child, and problems with healthcare personnel (Dalton et al., 2019; Ellis et al., 2017; Mack et al., 2017). Due to these reasons, parents' caregiver roles increase and their quality of life decreases (Modanloo et al., 2019). It is thought that it is inevitable that parents who have trouble taking time for themselves and resting during their child's illness experience fatigue and

sleep problems. These findings in the literature support the findings of the model in the study.

In our study, our model that included sociodemographic variables in addition to disease management showed an increase in difficulties in the management of the disease. These included an increase in parental age, decrease in education level, being in a nuclear family structure, having three or more children, the child diagnosed with cancer is in the 0–6 age group, the child's diagnosis is leukemia, hospitalization for more than 11 days. We determined that the increase in difficulties was a significant predictor of the increase in the level of fatigue and sleepiness (Table 4). When sociodemographic variables of the parent are included in the regression model, the explanatory power increased, as shown in Table 4, showing that these are important predictors of disease management. The literature suggests that fatigue and daytime sleepiness of parents are also affected by many factors, including the age of the parent, the age of the child, the diagnosis, the social support received, the treatment plan, the diagnosis of the child, the parent's level of coping, the communication between the spouses, the symptoms experienced by the child, the length of stay in the hospital, the fact that the parents have a large number of children, and that they have children at a young age (Nursyamsiyah, 2019; Salvador et al., 2015). Our study seems to be compatible with the literature.

Limitations

The first limitation of this research is that study data were collected from parents during the Covid-19 pandemic. There may be differences in the disease management and symptoms experienced by parents who have fear of infection, decreased interpersonal interaction and decreased social support during and cannot receive social support during the Covid-19 pandemic. Depending on this situation, parents may have experienced more fatigue and sleepiness and had difficulty in managing the disease. Another limitation is that the data in this study were collected from parents who were selected by the random sampling method in a single center, which may limit the generalization of study results across different populations. The third limitation is that the data collected in this study is based on self-report. It is recommended to include actigraphy or other objective measures of sleep and activity during the day, especially in future studies on fatigue and sleepiness. Although this study has some limitations, it also has many strengths. This study includes data from a very large sample group. In addition, parents of children with various types of cancer (leukemia, lymphoma, Nervous system tumor, solid tumor, other tumors etc.) were included in this study. These strengths contributed to the enrichment of the study. Another strength

that could be included is that self-report studies do allow ease of access for data collection, which contributes to the large sample size.

Conclusion

Childhood cancer is a family disease that affects parents as well as children. This is an important study revealing the effect of chronic disease management on the fatigue and daytime sleepiness of parents with children with cancer. Childhood cancers bring a lot of burden to the family due to symptoms, treatment methods, course of the disease, daily activity restrictions, and long-term effects and cause parents to experience physical and psychosocial risks. In addition, it is thought that training programs aiming which provide disease management support and which can be carried out by experts from different disciplines can increase parents' awareness about coping with the current disease and reduce the negative effects experienced.

Considering the outcomes of this study, nurses should be aware of the possible effects of disease management on the level of fatigue and daytime sleepiness. Nurses should not forget that families who cannot manage chronic diseases effectively and successfully may have high levels of fatigue and sleepiness. Therefore, these variables should also be addressed in nursing care plans. In addition, it is important to provide regular education on effective and sustainable disease management in pediatric oncology clinics. These education programs should be organized as one-on-one or group sessions and should be repeated intermittently to ensure the permanence of the education.

Acknowledgements We would like to thank to all participants.

Authors' contributions All the authors contributed to the concept and design, acquisition and interpretation of data, drafting the article and gave final approval of the version to be published.

Funding The authors received no financial support for the research, authorship, and/or publication of this article.

Data Availability There is no availability of data and material.

Declarations

Compliance with ethical statement There is no conflict of interest among the authors. The study was approved by the Non-Interventional Clinical Research Ethics Committee of a university (Decision No: 5759-GOA, 2020/27–08). The principal researcher explained the purpose of the study and obtained verbal and written informed consent from all participants.

Conflict of interest The authors have no funding or conflicts of interest to disclose. The authors have no conflicts of interest to disclose.

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