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ORIGINAL ARTICLE / ORİJİNAL MAKALE

Caregiver Reactions: A Cross Sectional Study on Caregivers of People with Dementia

Bakımveren Tepkileri: Demanslı Bireylerin Bakımverenleri Üzerine Kesitsel Bir Çalışma

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Abstract

Background: It is necessary to know comprehensively the caregiving reactions of caregivers and the affecting factors in order to improve the caregiving process.

Objective: To determine the caregiving reactions of caregivers of people with dementia and the affecting factors.

Method: The study was conducted with descriptive cross-sectional design. The sample consisted of 113 caregivers. Data was collected between January 2020 and January 2021.The t-test, Pearson's correlation analysis, and multiple linear regression analysis were used.

Results: The mean age of the caregivers was 54.95±11.242 and 77.9% of them were female. The mean scores of CRA subscales were 2.36±0.856 in the Financial Problems (7 variables in the models accounted for 34% of the variance-F = 5.326; R2 =.343; p = .000), 2.31 ± 0.886 in Lack of Family Support (3 variables accounted for 11% of the variance-F = 4.378; R2 = .108; p = .006), 2.75 ± 0.941 in Health Problems (10 variables accounted for 35% of the variance-F= 3.473; R2 = .349; p = .000), 3.33±0.955 in Disrupted Schedule (10 variables accounted for44% of the variance-F = 5.558; R2 = .443; p = .000), and 4.01 ± 0.595 in Caregiver's Self- Esteem.

Conclusion: The results of study highlight the importance of promoting a more holistic perspective toward caregiving for healthcare professionals.

Keywords: Dementia, Family, Caregiving, Caregiver Reactions

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Öz

Giriş: Bakım verme sürecini iyileştirmek için bakım verenlerin bakım verme tepkilerinin ve etkileyen faktörlerin kapsamlı bir şekilde bilinmesi gerekmektedir.

Amaç: Demanslı bireylere bakım verenlerin bakım verme tepkilerini ve etkileyen faktörleri belirlemektir.

Yöntem: Çalışma, tanımlayıcı kesitsel tasarımda yürütülmüştür. Örneklem 113 bakım verenden oluşmaktadır. Veriler Ocak 2020 ve Ocak 2021 tarihleri arasında toplanmıştır. t-testi, Pearson korelasyon analizi ve çoklu doğrusal regresyon analizi kullanılmıştır.

Bulgular: Bakım verenlerin yaş ortalaması 54.95 ± 11.242 ve %77.9'u kadındı. BTDÖ alt ölçeklerinin ortalama puanları Ekonomik Güçlükler 2.36 ± 0.856 (modellerdeki 7 değişken varyansın %34'ünü açıklamıştır-F = 5.326; R2 = ,343; p = .000), Aile Desteğinin Olmaması2.31 ± 0.886 (3 değişken varyansın %11'ini açıklamıştır-F = 4.378; R2 = .108; p = .006), Sağlık Üzerine Etkisi 2.75 ± 0.941 (10 değişken varyansın %35'ini açıklamıştır-F = 3.473; R2= .349; p = .000), Planların Bozulması 3.33 ± 0.955 (10 değişken varyansın %44'ünüaçıklamıştır-F = 5.558; R2= .443; p = .000) ve Benlik Saygısı 4.01 ± 0.595.

Sonuç: Çalışmanın sonuçları, sağlık profesyonelleri için bakım vermeye yönelik daha bütüncül bir bakış açısı geliştirmenin önemini vurgulamaktadır.

Anahtar Kelimeler: Demans, Aile, Bakım Verme, Bakım Verme Tepkileri

INTRODUCTION

More than 55 million people worldwide are estimated to have dementia (Alzheimer's Association [AA] 2021). It is predicted that the total number of people with dementia (PwD) would increasingly reach 78 million in 2030 and 139 million in 2050 (WHO, 2022). The cognitive, functional, and behavioral changes associated with dementia raise the degree to which PwD are in need of care, and also the needs of caregivers. PwD need the support of others to meet their physical, emotional, financial, and social needs. Family member caregivers often provide care to PwD in a variety of areas such as helping with activities of daily living such as nutrition, dressing, toileting, and bathing as well as mobilization, drug management, health check-ups, and medical appointments (AA 2021; Martínez-Santos et al., 2021). Many symptoms of PwD affect the lives of their caregivers in a variety of ways during caregiving (Lindeza et al., 2020, Schulz et al., 2020). Numerous studies on caregivers of PwD have indicated that the caregiving experience causes positive outcomes such as establishing a closer relationship with the PwD, improving caregiving skills, making out positive meaning and using humor albeit challenges, improving patience and tolerance, perceiving care as a sacred duty, gratitude, satisfaction, compassionate and empathetic approach, improved self- esteem, spiritual and personal development (Quinn et al., 2019; Jütten et al., 2020, Wang et al., 2022) as well as negative outcomes such as diabetes, hypertension, obesity, pain, depression, anxiety, sleep problems, impaired quality of life, disruption in family and social relationships, change in family roles, lack of support for care responsibility, failure to accept the disease, fear of failing to provide care in the future, believing that they are not understood, burnout) (Ashrafizadeh et al., 2021, Connors et al., 2020, Lindeza et al., 2020, Martínez- Santos et al., 2021, Tan et al., 2021).

There are studies that assess both the positive and negative caregiving reactions of caregivers; however, they are limited and outdated (Alvira et al., 2014, Ehrlich et al., 2014, Robinson et al., 2001). These studies have reported that caregivers are satisfied with the caregiving role; however, they face challenges in maintaining their daily lives and their economic situations during the caregiving (Ehrlich et al., 2014). Caregiver reactions are associated with the burden of the caregiver, quality of life, behavioral symptoms of patients, and activities of daily living (Alvira et al., 2014). Gender is an important variable. For example, female caregivers react more negatively to the behavioral symptoms of their patients (Robinson et al., 2001). While caregiver partners have problems in the Health Problems and Disrupted Schedule subscales, caregiver children have health problems (Wawrziczny et al., 2020). Many variables such as behavioral and functional symptoms of the PwD, their comorbidity, and the socio- demographic characteristics of the caregiver, such as age, gender, educational level, care burden, stress, depression and quality of life affect the reactions of caregivers (Alvira et al., 2014, Ehrlich et al., 2014 Robinson et al., 2001, Wawrziczny et al., 2020).

In the literature, there are a limited number of outdated studies on the reactions of caregivers to PwD (Alvira et al., 2014, Ehrlich et al., 2014 Robinson et al., 2001). No comprehensive study that assessed characteristics of both patients and caregivers was found in the literature. A recent qualitative study investigating the caregiving experiences of caregivers of PwD suggests that studies should be conducted on the variables causing positive and negative experiences (Ashrafizadeh et al., 2021). It is important to conduct a comprehensive examination on the reactions of caregivers and the affecting factors and to plan effective interventions for caregivers.

Aim

In this study, it was aimed to determine the caregiving reactions of family member caregivers of PwD and the affecting factors.

METHOD

Type of the Research

Descriptive cross-sectional design was used in this study.

Universe/Sample of the Research

The study was conducted with a total of 113 family member caregivers of PwD who applied to the Department of Geriatrics and the Dementia Outpatient Clinic of the Department of Neurology, the Faculty of Medicine of a University Hospital and were enrolled in the X Branch of the Alzheimer's Association, between January 2020 and January 2021. As a result of the post-hoc analysis, the power of the study was found to be 84% based on the effect size of d=0.15 (moderate effect), significance level of < 0.05, sample size of 113, and 8 variables in multiple regression analysis using G-power 3.1 program.

Data Collection Instrument-Validity and reliability information

Table 1 shows the data collection tools used in the study.

Table 1. Study Measures, Scoring, and Reliability

Measure	Number of Items	Description	Scoring and reliability
Caregiver Reaction Assessment Scale - TUR (Bahar et al., 2017)	24	It assesses five dimensions of the caregiver reaction: financial problems, lack of family support, health problems, disrupted schedule, and caregiver's self-esteem.	5-point Likert-type scale with 1= strongly disagree to 5 = strongly agree (Cronbach's α value is .83 in disrupted schedule, .84 in self- esteem, .81 in financial problems, .80 in lack of family support and .70 in health problems. Cronbach's α values were .78, .70, .66, .75 and .68,respectively in the current study)
Neuropsychiatric Inventory-TUR (Kalem et al., 2005)	12	Presence and severity of neuropsychiatric symptoms	Its total score is 144 points. The numeric values assigned for the frequency (1 rarely, 2 sometimes,3 frequently, 4 very frequently) and severity (1 mild, 2 moderate, 3 severe) of the symptoms are multiplied to obtain the score for that domain. (Cronbach's α = .79)
Standardized Mini Mental Test-TUR for Educated and Uneducated People (Keskinoğlu et al. 2009)	11	It assesses cognitive performance under five major headings: orientation, record memory, attention and calculation, recall and language.	Its total score is 30 points. A score of 22 and below for educated people and 18 and below for uneducated people indicate cognitive impairment. (Cronbach's α = .92)
Activities of Daily Living Scale - TUR (Tel, Güler and Tel 2011)	6	It assesses simple activities of daily living (such as bathing, dressing, and toileting) for functional disabilities and dependence.	Its total score is 18 points. According to the scale, 0-6 points are assessed as dependent, 7-12 points as semi-dependent, and 13-18 points as independent. (Cronbach's α = .75)
Instrumental Activities of Daily Living Scale - TUR (Tel, Güler and Tel 2011)	8	It assesses the activities necessary for the person to live independently in the public (such as using the telephone, preparing food, shopping, etc.).	Its total score is 24 points. 0-8 points are assessed as dependent, 9-16 points as semi-dependent, and 17-24 points as independent. (Cronbach's α = .73)
Charlson Comorbidity Index	19	It estimates mortality by classifying the conditions of comorbid diseases and assessing their severity.	Its total score is 37 points. The index is rated between 1 and 6 points based on its severity

The data collection was started by holding face-to-face interviews; however, the COVID-19 pandemic broke out; therefore, data were collected from 61 people over the phone. The study was reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist: cross-sectional studies (available at www.strobe-statement.org).

Evaluation of the Data

The data were assessed using IBM SPSS Statistics Premium Academic Pack - Concurrent User V 25 ,number and percentage distributions as descriptive statistics as well as correlation and multiple regression analysis. Before the multiple regression analysis, the multi-collinearity test was applied to determine the correlation between the affecting factors and the dependent variable. Independent variables with a variance inflation factor (VIF)— a measure of multi-collinearity— of < 10 and a tolerance of > 0.20 was included in the model.

Ethical Aspect of the Research

The institutional permission and ethics committee approval (dated 20/01/2020, file number 5140-GOA and decision number

2020/02-24) were obtained for the conduct of the study. Participation in the study was based on voluntariness, and verbal and written consents were obtained from the participants.

RESULTS

Caregivers

The mean age of the caregivers was 54.95 ± 11.242 (min-max: 24 - 82), the duration of caregiving (year) was 4.24 ± 2.769 (min-max: 1 - 15), and their CCI mean score was 1.98 ± 1.658 (min-max: 0 - 7). The mean age of the PwD was 75.75 ± 8.864 (min-max: 56-97), their CCI mean score was 5.63 ± 1.681 (min-max: 2 - 11), their MMSE mean score was 14.80±7.060

(min-max: 2 - 29), their NPI mean score was 55.52 ± 18.785 (min-max: 9 - 128), their ADL mean score was 13.12 ± 3.926 (0-18), and their IADL mean score was 9.75 ± 3.639 (min- max: 0 - 24). Table 2 shows the participants' mean scores of the CRA subscales based on their socio-demographic and clinical characteristics.

Table 2. Comparison of the Participants' scores on the Caregiver Response Assessment Scale Based on their Demographic and Clinical Characteristics

Caregiver Reaction Assessment Scale

Caregivers' (n=113)	**Financial problems**	**Lack ofFamily Support**	**Health Problems**	**Disrupted schedule**	**Caregiver's Self-Esteem**
	X ± SD	**X ± SD**	**X ± SD**	**X ± SD**	**X ± SD**
Gender					
Female (77.9%)	2.41 ± 0.824	2.35 ± 0.905	2.92±0.922	3.46±0.924	4.00 ± 0.529
Male (22.1%)	2.16 ± 0.952	2.16 ± 0.819	2.17±0.773	2.89±0.949	4.04 ± 0.798
	Z=-1.475	Z=-0.859	Z=-3.510	Z=-2.419	Z=-1.258
	p=.140	p=.391	p=.000*	p=.016*	p=.208
Educational Level					
Primary Education and Less (25.7%)	2.76 ± 0.945	2.59 ± 0.969	3.19±0.949	3.52±0.916	3.96 ± 0.448
High School (22.1%)	2.22 ± 0.700	2.20 ± 0.772	2.58±0.868	3.25±0.912	4.09 ± 0.563
University (52.2%)	2.21 ± 0.819	2.21 ± 0.873	2.61±0.914	3.28±0.995	4.01 ± 0.672
	X^2=7.129	X^2=2.995	X^2=8.377	F=.739	X^2=1.612
	p=.028*	p=.224	p=.015*	p=.480	p=.447
	Difference= (1-3)	-	Difference =(1-2). (1-3)	-	-
Marital Status					
Single (25.7%)	2.51 ± 0.768	2.46 ± 1.054	2.76±0.929	3.51±1.075	3.89 ± 0.780
Married (74.3%)	2.30 ± 0.882	2.25 ± 0.821	2.75±0.951	3.27±0.909	4.05 ± 0.516
	Z=-1.695	Z=-.889	Z=-.304	Z=-1.255	Z=-.650
	p=.090	p=.374	p=.761	p=.209	p=.515
Employment Status					
Employed (35.4%)	2.16 ± 0.765	2.12 ± 0.932	2.38±0.866	3.06±1.072	4.09 ± 0.748
Unemployed (64.6%)	2.46 ± 0.889	2.40 ± 0.851	2.96±0.922	3.48±0.855	3.97 ± 0.492
	Z=-1.582	Z=-2.212	Z=-3.201	t=-2.325	Z=-1.921
	p=.114	p=.027*	p=.001*	p=.033*	p=.055
Monthly Income					
Income Less Than Expenditures (22.1%)	2.98 ± 0.947	2.46 ± 0.834	3.10±0.835	3.82±0.861	4.04 ± 0.481

Table 2. (Continue) Comparison of the Participants' scores on the Caregiver Response Assessment Scale Based on their Demographic and Clinical Characteristics

Income Equal to Expenditures (58.4%)	2.29 ± 0.750	2.36 ± 0.921	2.78±0.978	3.29±0.898	4.02 ± 0.561
Income More Than Expenditures (19.5%)	1.86 ± 0.640	1.96 ± 0.780	2.28±0.769	2.91±1.023	3.96 ± 0.806
	X^2=20.168	**X^2**=4.914	**X^2**=9.706	**X^2**=10.77	**X^2**=.253
	p=.000*	**p**=.086	**p**=.008*	**p**=.005*	**p**=.881
	Difference = (1-3), (1-2)	-	Difference = (1-3)	Difference = (1-3), (1-2)	-
Level of Relationship with the patient					
Daughter (51.3%)	2.36 ± 0.796	2.34 ± 0.961	2.85±0.949	3.58±0.878	4.06 ± 0.564
Son (13.3%)	2.11 ± 1.015	1.91 ± 0.684	1.98±0.658	2.93±1.218	4.13 ± 0.928
Spouse (31.0%)	2.43 ± 0.929	2.44 ± 0.780	2.94±0.924	3.16±0.872	3.90 ± 0.493
Relative (4.4%)	2.58 ± 0.438	2.16 ± 1.108	2.60±0.720	2.84±0.921	3.94 ± 0.321
	X^2=3.205	**X^2**=4.652	**F**=3.181	**X^2**=8.544	**X^2**=7.266
	p=.361	**p**=.199	**p**=.027*	**p**=.036*	**p**=.064
	-	-	Difference =(1-2), (1-3)	Difference = (1-2), (1-3)	-
Has he/she previously provided care?					
Yes (77.0%)	2.33 ± 0.898	2.28 ± 0.946	2.76±0.968	3.39±0.943	4.05 ± 0.615
No (23.0%)	2.44 ± 0.703	2.40 ± 0.655	2.72±0.861	3.14±0.991	3.89 ± 0.513
	Z=-.762	**Z**=-1.245	**Z**=-.127	**Z**=-1.203	**Z**=-1.545
	p=.446	**p**=.213	**p**=.899	**p**=.229	**p**=.122
Is there any care assistant?					
Yes (67.3%)	2.34 ± 0.836	2.67 ± 0.807	2.76±1.004	3.12±1.014	3.93 ± 0.533
No (32.7%)	2.37 ± 0.871	2.13 ± 0.873	2.75± 0.916	3.44± 0.914	4.05 ± 0.623
	Z=-.342	**Z**=-3.324	**Z**=-.135	**t**=1.666	**Z**=-1.690
	p=.732	**p**=.001*	**p**=.892	**p**=.098	**p**=.091
People with Dementia (n=113)					
Dementia Type					
AD (64.6%)	2.25 ± 0.819	2.37 ± 0.895	2.63±0.905	3.28±0.980	3.99 ± 0.647
VD (9.7%)	2.63 ± 1.073	1.98 ± 0.883	2.93±0.783	3.51±0.659	3.89 ± 0.509
FTD (11.5%)	2.35 ± 0.894	2.28 ± 0.918	2.98±1.101	3.36±1.023	4.32 ± 0.447
DLB (14.2%)	2.64 ± 0.810	2.26 ± 0.850	3.01±1.041	3.43±1.017	3.97 ± 0.459
	X^2=3.904	**X^2**=2.193	**X^2**=3.075	**X^2**=.800	**X^2**=4.985
	p=.272	**p**=.533	**p**=.380	**p**=.849	**p**=.173
Dementia Stage					
Early Stage (27.4%)	1.98 ± 0.690	2.23 ± 0.662	2.36±0.866	2.61±0.789	3.94 ± 0.539
Moderate Stage (46.9%)	2.35 ± 0.880	2.29 ± 0.925	2.68±0.865	3.40±0.864	3.98 ± 0.675
Advanced Stage (25.7%)	2.76 ± 0.810	2.40 ± 1.035	3.30±0.929	3.99±0.747	4.16 ± 0.478
	X^2=12.534	**X^2**=.107	**X^2**=14.265	**X^2**=32.834	**X^2**=3.004
	p=.002*	**p**=.948	**p**=.001*	**p**=.000*	**p**=.223
	Difference =(1-3)	-	Difference =(1-3), (2-3)	Difference =(1-2), (1-3),(2-3)	-

t: Independent Sample t-Test, Z: Mann Whitney U Test, F: One-way Analysis of Variance, X^2: Kruskal Wallis H Test

**p < .05 (Significant at Confidence Interval of 95%), AD: Alzheimer's Disease, VD: Vascular Dementia, FTD: Frontotemporal Dementia, DLB: Dementia with Lewy Bodies*

A weak positive statistically significant correlation was found between the age of the caregivers and their scores of the Lack of Family Support (LFS) subscale ($r = .277$; $p = 003$). There was a weak negative correlation between the age of the caregivers and their scores of the Caregiver's Self-Esteem (SE) subscale ($r = -.23$; $p = .011$). A weak positive and significant correlation was found between the duration of caregiving and score of the Disrupted Schedule (DS) subscale ($r = .21$; $p = .023$). There was a weak positive correlation between the caregivers' CCI and LFS scores ($r = .21$; $p = .000$). No significant correlation was found between their scores of CCI and Financial Problems (FP), Health Problems (HP), DS, and SE subscales ($p > 0.05$).

PwD

There was no significant correlation between the age of the PwD and their CRA scores ($p > 0.05$). Table 3 shows the correlation between some clinical characteristics of PwD and their CRA scores.

Table 3. The Correlation Between the Scores of Charlson Comorbidity Indices, Mini-Mental Test, Neuropsychiatric Inventory, Activities of Daily Living Scale and Instrumental Activities of Daily Living Scale and the Scores of Caregiver Reaction Assessment Scale in People With Dementia

Caregiver Reaction Assessment Scale		CCI	MMT	NPI	ADL	IADL
Financial Problems	r	.103	-.336	.295	-.365	-.364
	p	.280	.000*	.002*	.000*	.000*
Lack of Family Support	r	.092	.008	-.049	-.002	-.042
	p	.334	.931	.604	.985	.658
Health Problems	r	.032	-.295	.276	-.313	-.290
	p	.738	.002*	.003*	.001*	.002*
Disrupted schedule	r	.032	-.479	.324	-.516	-.523
	p	.734	.000*	.000*	.000*	.000*
Caregiver's Self-Esteem	r	.007	-.133	-.188	-.202	-.118
	p	.945	.161	.047*	.032*	.215

** p < .05 (Significant at 95% of Confidence Interval), CCI: Charlson Comorbidity Index; MMT: Mini Mental Test, NPI: Neuropsychiatric Inventory, ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living*

Financial Problems Caregivers

It was found that the educational level of the caregivers statistically significantly accounted for 8% of the variance on FP score ($F = 4.688$; $R^2 = .028$; $p = .011$). The educational levels of high school and university predicted the FP score in a negatively and statistically significantly manner ($p < 0.05$). According to the standardized regression coefficient (β), the relative order of importance of the predictor variables on FP score was university ($\beta = -.323$) and high school ($\beta = -.262$).

The income level of the caregivers statistically significantly accounted for 19% of the variance on FP score ($F = 12.672$; $R^2 = .187$; $p = .000$). Having an income equal to expenses and income more than expenses predicted the FP score in a negatively and statistically significantly manner ($p < 0.05$). According to the standardized regression coefficient, the relative order of importance of the predictor variables on FP score was income more than expenses ($\beta = -519$) and income equal to expenses ($\beta = -.399$).

PwD

Dementia stage (accounted for 11% of the variance, $F = 6.835$; $R^2 = .111$; $p = .002$, advanced stage ($\beta = .399$) and moderate stage ($\beta = .219$)), MMSE (accounted for 11% of the variance, $F = 13.027$; $R^2 = .105$; $p = .000$, predicted negatively and statistically significant $\beta = -.324$; $p < 0.05$), NPI (accounted for 8% of the variance, $F = 10.617$; $R^2 = ,080$; $p = .001$, predicted positively and statistically significantly $\beta = .295$; $p < 0.05$), ADL (accounted for 15% of the variance, $F = 19.788$; $R^2 = ,151$; $p = .000$, predicted positively and statistically significantly $\beta = .389$; $p < 0.05$) and IADL (accounted for 10% of the variance, $F = 12.268$; $R^2 = .100$; $p = .001$, predicted negatively and statistically significant $\beta = -.315$; $p < 0.05$) affected score of the FP subscale.

The variables in the model statistically significant accounted for 34% of the variance on FP score ($F = 5.326$; $R^2 = .343$; $p = .000$) (Table 4). The most significant predictor of FP among the variables was monthly income status.

Table 4. Analysis of the Impact on the Financial Problems Subscale with Multiple Linear Regression Analysis

Variable	B	S.E.	β	t	p	R	R2	F	p
Constant	3.306	.659		5.020	.000*				
Caregiver's Education (High School)	-.354	.205	-.172	-1.721	.088				
Caregivers Education (University)	-.351	.177	-.206	-1.987	.050				
Monthly Income (Income Equal to Expenditure)	-.584	.182	-.338	-3.202	.002*				
Monthly Income (Income more than Expenditure)	-.888	.235	-.413	-3.784	.000*				
Dementia Stage (Moderate Stage)	-.018	.237	-.011	-.077	.939	.586	.343		5.326
Dementia Stage (Advanced Stage)	.007	.402	.003	.017	.987				
MMT	-.001	.021	-.006	-.035	.972				
NPI	.008	.004	.183	1.891	.061				
ADL	-.035	.039	-.161	-.903	.369				
IADL	-.016	.035	-.069	-.466	.642				

** p < .05 (Significant at Confidence Interval of 95%), MMT: Mini Mental Test, NPI: Neuropsychiatric Inventory, ADL: Activities of Daily Living, IADL: Instrumental Activitie of Daily Living*

Lack of Family Support Caregivers

It was determined that the age of the caregiver statistically significantly accounted for the variance on LFS score ($F = 8.170$; $R^2 = .069$; $p = .005$) by 7% and predicted it in a positive and statistically significant manner ($\beta = .262$; $p < 0.05$). Having a care assistant statistically significantly accounted for 8% of the variance on LFS score ($F = 10.083$; $R^2 = .083$; $p = .002$) and predicted

it negatively and statistically significantly ($\beta = .289$; $p < 0.05$). The Charlson Comorbidity Index of the caregivers statistically significantly accounted for 4% of the variance on LFS score ($F = 4.592$; $R^2 = .040$; $p = .034$) and predicted it in a positive and statistically significant manner ($\beta = .199$; $p < 0.05$). Employment status was not a significant predictor ($p > 0.05$). The variables in the model statistically significantly accounted for 11% of the variance on LFS score ($F = 4.378$; $R^2 = .108$; $p = .006$) (Table 5).

Table 5. Analysis of the Impact on the Lack of Family Support Subscale with Multiple Linear Regression Analysis

Variable	B	S.E.	β	t	p	R	R2	F	p
Fixed	1.866	.571		3.266	.001*				
Caregiver's Age	.013	.011	.161	1.173	.243	.328	.108	4.378	.006*
Having A Care Assistant	-.408	.187	-.217	-2.177	.032*				
Caregiver's CCI	.007	.070	.013	.102	.919				

** p < .05 (Significant at Confidence Interval of 95%), CCI: Charlson Comorbidity Index*

Health Problems Caregivers

It was determined that being female statistically significantly accounted for 11% of the variance on HP score (F = 13.647; R^2 = .109; p = .000) and predicted it in a positive and statistically significant manner (β = .331; p < 0.05). The educational level statistically significantly accounted for 8% of the variance on HP score (F = 4.493; R^2 = .076; p = .013). The educational levels of university (β = -.309) and high school (β = -.270) predicted HP in a negative and statistically significant manner (p < 0.05). Being employed statistically significantly accounted for 8% of the variance on HP score (F = 10.787; R^2 = .080; p = .013) and predicted it in a negative and statistically significant manner (β = .298; p < 0.05). The income status statistically significantly accounted for 8% of the variance on HP score (F = 4.745; R^2 = .079; p = .011). Having an income equal to expenses (β = -.171) and an income more than expenses (β = -.345) negatively and statistically significantly predicted HP score (p < 0.05). The level of relationship with patient statistically significantly accounted for 11% of the variance on HP score (F = 4.412; R^2 = .108; p = .006). Being a caregiver son (β = .464), spouse (β = .470) and relative (β = .135) of PwD predicted the HP score in a positive and statistically significant manner (p < 0.05).

PwD

Dementia stage (accounted for 14% of the variance, F = 8.796; R^2 = .138; p = .000, advanced stage (β = .437) and moderate stage (β = .168), MMSE (accounted for 9% of the variance, F = 10.771; R^2 = .088; p = .001, predicted negatively and statistically significantly β = -.297; p < 0.05), NPI (accounted for 6% of the variance, F = 6.399; R^2 = .055; p = .013, predicted positively and statistically significantly β = .233; p < 0.05), ADL (accounted for 14% of the variance, F = 17.429; R^2 = .136; p = .000, predicted negatively and statistically significantly β= .368; p < 0.05) and IADL (accounted for 8% of the variance, F = 8.942; R^2 = .075; p = .003, predicted negatively and statistically significantly β = -.273; p < 0.05) affected score of the HP subscale. It was observed that the variables in the model statistically significantly accounted for 35% of the variance on HP score (F = 3.473; R^2 = .349; p = .000) (Table 6).

Table 6. Analysis of the Impact on the Health Problems Subscale with Multiple Linear Regression Analysis

Variable	B	S.E.	β	t	p	R	R^2	F	p
Constant	2.490	.799		3.116	.002*	.591	.349	3.473	
Caregiver's Gender (Female)	.408	.298	.181	1.369	.174				
Caregiver's Education (High School)	-.372	.265	-.165	-1.402	.164				
Caregiver's Education (University)	-.250	.254	-.133	-.983	.328				
Caregiver's Employment (Employed)	-.276	.225	-.141	-1.224	.224				
Monthly Income (Income Equal to Expenditure)	-.054	.206	-.028	-.262	.794				
Monthly Income (Income more than Expenditure)	-.108	.283	-.045	-.381	.704				
Level of Relationship with the Patient (son)	.181	.410	.097	.442	.659				
Level of Relationship with the Patient (daughter)	.496	.391	.245	1.268	.208				
Level of Relationship with the Patient (relative)	.306	.567	.067	.540	.590				
Dementia Stage (Moderate Stage)	.402	.272	.214	1.482	.142				
Dementia Stage (Advanced Stage)	.886	.454	.413	1.951	.054				
MMT	.021	.024	.158	.868	.388				
NPI	.000	.005	.004	.041	.967				
ADL	-.037	.045	-.153	-.821	.414				
IADL	-.022	.042	-.084	-.520	.604				

** p < .05 (Significant at Confidence Interval of 95%), MMT: Mini Mental Test, NPI: Neuropsychiatric Inventory, ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living*

Disrupted Schedule Caregivers

It was found that being female statistically significantly accounted for 6% of the variance on DS score ($F = 7.322$; $R^2 = .062$; $p = .008$). Being a female caregiver predicted DS score in a positive and statistically significant manner ($\beta = .249$; $p < 0.05$). Being employed statistically significantly accounted for 5% of the variance on DS score ($F = 5.405$; $R^2 = .046$; $p = .022$).

Being an employed caregiver predicted DS score in a negative and statistically significant manner ($\beta = -.215$; $p < 0.05$). The income status statistically significantly accounted for 10% of the variance on DS score ($F = 5.976$; $R^2 = .098$; $p = .003$). Having an income equal to expenses and an income more than expenses predicted DS score in a negative and statistically significant manner ($p < 0.05$). According to the standardized regression coefficient, the relative order of importance of the predictor variables on DS score was an income more than expenses (β = -,379) and an income equal to expenses ($\beta = -.276$). The level of relationship with the patient statistically significantly accounted for 8% of the variance on DS score ($F = 3.181$; $R^2 = .080$; $p = .027$). Being a caregiver son and spouse of PwD predicted DS score in a positive and statistically significant way and being a caregiver relative predicted it in a negative and statistically significant manner ($p < 0.05$). According to the standardized regression coefficient, the relative order of importance of the predictor variables on DS score was being a caregiver son ($\beta = .340$), spouse ($\beta = .110$) and relative ($\beta=.020$) of PwD. The duration of caregiving statistically significantly accounted for 6% of the variance on DS score ($F = 6.415$; $R^2 = .055$; $p = .013$). The duration of caregiving predicted DS score in a positive and statistically significant manner ($\beta = .234$; $p < 0.05$).

Table 7. Analysis of the Impact on the Disrupted Schedule Subscale with Multiple Linear Regression Analysis

Variable	B	S.E.	β	t	p	R	R^2	F	p
Constant	3.588	.732		4.899	.000*				
Caregiver's Gender (Female)	.321	.263	.140	1.220	.225				
Caregiver's Employment (Employed)	-.531	.198	-.267	-2.690	.008*				
Monthly Income (Income Equal to Expenditure)	-.395	.190	-.205	-2.077	.040*				
Monthly Income (Income more than Expenditure)	-.373	.269	-.155	-1.389	.168				
Level of Relationship with the Patient (son)	-.157	.358	-.082	-.438	.663				
Level of Relationship with the Patient (daughter)	-.196	.369	-.095	-.530	.597				
Level of Relationship with the Patient (relative)	-.723	.508	-.156	-1.422	.158	.665	.443	5.558	
Duration of Caregiving	.010	.032	.028	.298	.766				
Dementia Stage (Moderate Stage)	.646	.254	.339	2.548	.012*				
Dementia Stage (Advanced Stage)	.899	.425	.413	2.113	.037*				
MMT	.013	.021	.094	.593	.555				
NPI	.002	.005	.038	.407	.685				
ADL	-.010	.042	-.040	-.233	.816				
IADL	-.060	.040	-.228	-1.491	.139				

** p < .05 (Significant at Confidence Interval of 95%), MMT: Mini Mental Test, NPI: Neuropsychiatric Inventory, ADL: Activities of Daily Living, IADL: Instrumental Activities of Daily Living*

PwD

Dementia stage (accounted for 29% of the variance, $F = 21.873$; $R^2 = .285$; $p = .000$, advanced stage ($\beta = .635$) and moderate stage ($\beta = .414$), MMSE (accounted for 21% of the variance, $F = 29.859$; $R^2 = .212$; $p = .000$, predicted negatively and statistically significantly $\beta = -.460$; $p < 0.05$), NPI (accounted for 11% of the variance, $F = 14.048$; $R^2 = .112$; $p = .000$, predicted positively and statistically significantly $\beta = .335; p < 0.05$), ADL (accounted for 25% of the variance, $F = 37.723; R^2 = .254; p = .000$, predicted positively and statistically significantly $\beta = .504; p < 0.05$) and IADL (accounted for 24% of the variance, $F = 35.626; R^2 = .243; p = .000$, predicted negatively and statistically significantly $\beta = -.493; p < 0.05$) affected score of the DS subscale. It was observed that the variables in the model statistically significantly accounted for 44% of the variance on DS score ($F = 5.558; R^2 = .443; p = .000$) (Table 7).

Caregiver's Self-Esteem

For Caregivers: It was found that the age of the caregivers had no statistically significant effect on the Caregiver's SE subscale ($p = 0.06$). For PwD, ADL affected the SE subscale (accounting for 4% of the variance, $F = 5.103; R^2 = .044; p = .026$, predicted it in a negative and statistically significantly way ($\beta = -.210; p < 0.05$).

DISCUSSION

For Caregivers

Financial Problems

It was found that the caregivers had moderate FP. Caregivers had moderate FP in similar studies (Cobb et al., 2016, Igarashia et al., 2020, Liao et al., 2020). The mean age of the caregivers included in this study was 54.95 years. Individuals having a mean age are assumedto be actively employed. It is thought that if these individuals, who can contribute to the family economy, have to temporarily leave their job or have to resign from their job due to caregiving, this may cause a reduction in their income and, consequently, lead to financial problems.

It was found that the educational level and income status of the caregivers predicted the FP subscale. Another study reported that caregivers had a low level of FP which was not correlated with the educational level (Ehrlich et al., 2014). These differences may be attributed to different income levels of the individuals living in the countries in which the studies were carried out. Given better working conditions and living standards, it is thought that people with higher levels of education and income had less FP during caregiving.

Lack of Family Support

It was found that LFS caused caregivers to give a moderate negative reaction. Likewise, it was observed in the literature that the LFS caused a moderate level of caregiver reaction (Ehrlich et al., 2014, Cobb et al., 2016). It was reported that the mental health of caregivers who have weak family dynamics and are unable to get enough support from other family members is impaired, their psychological well-being is low, they have difficulties in their caregiving role, and their care burden increases (Alvira et al., 2014). It is known that caregivers who have strong family dynamics provide better quality care (Panyavin et al., 2015).

It was found in this study that the age of the caregivers, the presence of a care assistant and CCI scores were correlated with LFS and these variables predicted LFS. As the age of the caregiver increases, the caregiver suffers more from HP and has difficulties in carrying out his/her ADL and meeting his/her needs. Caregivers are incapable to meet their care needs due to health conditions of both their own and PwD (AA 2021). Therefore, as caregivers get older, they need more support in the caregiving and react more negatively to LFS in this regard.

It was observed that the presence of a care assistant was inversely proportional to LFS. If there is a care assistant, caregivers feel the family's support and react less negatively toward caregiving. The caregiving responsibilities are shared with a care assistant. The presence of a care assistant is expected to be an important factor in reducing the reactions of the caregiver. It is thought that people with strong family support would have less psychological distress in caregiving and their negative reactions would reduce. The comorbidity of the caregivers was determined to be one of the variables that predicted LFS. Maintaining the care of PwD causes caregivers to experience problems, such as depression, anxiety, and sleeplessness, and raises their CCI scores (Montgomery et al., 2018). Given their own care needs, caregivers need more family support as their comorbidities increase. Therefore, this study suggests that as the CCI score of the caregivers increased, their negative reaction associated with LFS increased.

Health Problems

The effect of caregiver reactions on health was found to be moderate. In the literature, it was reported that 40% of the caregivers of PwD stated their health condition as moderate (De Fazio et al., 2015). It was reported that caregivers of PwD had an impaired quality of life compared to those who were not caregivers and they had a more sedentary life (Madruga et al., 2020).

In the present study, it was found that variables of caregivers' gender, educational level, employment, monthly income, and level of relationship with the patient predicted HP. When the literature was examined, it was observed that male caregivers had fewer HP (Cobb et al., 2016), female caregivers described their own health conditions as worse than male ones and experienced more care burden, their physical health was more negatively affected, and they had higher levels of perceived stress, depression and anxiety (De Fazio et al., 2015, Xiong et al., 2020), which supported gender finding of the present study.

It was found that the caregivers with low educational levels had more negative reactions toward health problems. It is known that caregivers with high educational levels have better physical health and quality of life and apply outpatient clinic more (Tülek et al., 2020, Zhu et al., 2015). It is thought that high educational level positively affects the use of health services, awareness of health conditions, regular health check-ups, adherence to the treatment plan in case of comorbidity, and self-care skills, thus resulting in a lower level of caregiver reaction toward health problems.

It was determined that income level affected the caregiver's reaction, and the impact of caregiver's reaction on health was more negative in individuals with low level of income. It is thought that individuals with low levels of income are incapable of meeting their basic needs such as personal care, nutrition and access to health systems, and consequently, their health conditions are negatively affected and caregivers would have more negative reactions toward health problems. A recent review by Nguyen and Comans (2021) emphasized that studies making financial assessment so far often underestimated the perspectives of caregivers and the costs and outcomes associated with caring for their relatives with dementia. The researchers pointed out that there may also be invisible and unaccountable caregiving costs. Many studies revealed that the variables related to the economic conditions of caregivers such as employment and income status were not thoroughly examined. It is thought that future studies should investigate the impacts of environmental, social, cultural and economic factors on health.

It was found that the level of relationship with the patient affected the caregiver reactions and partners had more negative caregiver reactions to health problems. It was reported that caregiver partners had lower quality of life associated with physical health and poor health conditions (Chen et al., 2020, Zhu et al., 2015). It is thought that caregiver partners have higher negative reactions related to health problems as they are older than their major children and thus have more comorbidities.

Disrupted Schedule

Caregiver reactions were also found to be at a moderate level for the subscale of DS. Likewise, it was observed in the literature that DS caused a moderate level of caregiver reaction (Ehrlich et al., 2014, Cobb et al.,2016). ADL of caregivers were affected by the process of caregiving, leading to withdrawal from daily activities and social isolation (Lindeza et al., 2020, Madruga et al., 2020, Martínez-Santos et al., 2021). All caregivers, who had allocated time for themselves before, had social difficulties during the caregiving since the number of people who would visit them at home was reduced, and more than half of them had no time for themselves and were unable to go out (Zhu et al., 2015). It is considered that caregivers disrupt their plans due to the responsibility of caregiving, spending most of their time with caregiving, prioritizing the needs of the individual they care for rather than their own needs, making sacrifices, and they lack of sufficient family and social support in care.

It was found that gender predicted DS and the plans of female caregivers were disrupted more when compared to male caregivers. There are similar results in the literature (Ehrlich et al., 2014). It is known that women in many societies often do household chores and take more caring roles. The roles and responsibilities of women increase along with caregiving. It is thought that the ADL of women are affected more due to the roles attributed to them and they have higher DS scores compared to their male counterparts.

It was found that employment and monthly income predicted disrupted schedule, and caregiver reaction toward DS was higher in individuals who were unemployed and had a low level of income. It is thought that individuals who are employed and have a high level of income are less interested in the individual they care for since they work during the day and are away from the patient, which affects their mental health, sociability and daily life to a lesser extent; therefore, it is considered that they have less caregiver reaction toward the DS compared to non-employed individuals.

It was found that the level of relationship with the patient predicted DS, and the caregiver reaction toward DS was greater in caregivers who were daughters of the patient. It has been reported that caregivers who are children of patients have a lower quality of life and more care burden (Rigby et al., 2019) and have higher negative reactions toward DS (Wawrziczny et al., 2020). As daughters, caregivers have more than one role in their daily lives, such as being employed, raising children, and doing household chores. It is believed that these roles place more burden on them, which causes their plans to be disrupted.

It was found that the duration of caregiving had a positive statistically significant correlation with DS. The duration of caregiving was positively correlated with the severity of dementia. The increased severity of dementia in the patients requires more support in the field of care and the prolonged duration of caregiving. It is considered that the disruption of caregiver plans is inevitable as they spend more time in care of their patients.

Caregiver's Self-Esteem

It was found in the present study that the caregiver's SE subscale was at a good level. Similar findings were observed (Cobb et al., 2016, Sittironnarit et al., 2020). A study reported that the SE of caregivers was at a moderate level (Ehrlich et al., 2014). Another study showed that a close relationship between the caregiver and the PwD and the low depression level of the caregiver positively affected SE of the caregivers (Jütten et al., 2020).

In this study, it was observed that the majority of caregivers were female and daughters. Both socially and culturally, the role of care is mostly attributed to women and daughters. They are appreciated by their family and social circles for managing the responsibility of care. Therefore, it is believed that caregiving leads to an improvement in self-confidence, feeling well, and commitment to the caregiving role. These are thought to positively affect the caregiver's reaction and contribute to improved SE.

PwD

This study revealed that the clinical characteristics of the PwD were correlated with the dementia stage, MMSE, NPI, ADL, IADL and FP, HP, and DS subscales of CRA. Especially the neuropsychiatric symptoms and functional impairments of PwD are closely correlated with the care burden (Feast et al., 2016, İlik et al., 2020, Reed et al., 2019).

As PwD have difficulty in carrying out their own daily activities and their dependence on caregivers increases, it is considered that caregivers provide more physical care and consequently have more HP. As the care needs increase, care expenditures increase, and this may put caregivers in economic hardship. The increase in the dependence level of the PwD requires more supervision. Therefore, there may be changes in the daily plans of caregivers. It is considered that their daily routines vary due to the follow-up of treatment and symptoms of their patients, and thus, their schedules are increasingly disrupted, as well.

IMPLICATIONS FOR PRACTICE

It was concluded that the family member caregivers of the PwD exhibited moderate negative reactions toward FP, LFS, HP, and DS, while they displayed high positive reactions toward SE. The caregivers displayed more negative reactions toward the caregiving.

It was concluded that the reaction of the caregivers was affected by their descriptive characteristics as well as the clinical characteristics of the PwD (dementia stage, MMSE, NPI, ADL, IADL). It is therefore recommended to develop interventions for the clinical variables of PwD, as the affecting factors identified in this study, and it is thought that the negative reactions of caregivers would subside accordingly and this study would contribute to raising the awareness of nurses about caregivers of PwD.

In this study, it is thought that the Caregiver Reaction Assessment Scale is limited in identifying the positive reactions of caregivers since it has only one subscale for positive reactions. Consequently, further studies are required to identify and promote positive reactions of caregivers toward caregiving and the affecting factors.

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