

The Strain and Hopelessness in Family Caregivers of Patients with Gynecologic Cancer Receiving Chemotherapy

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ABSTRACT

This study aimed to investigate strain and hopelessness among family caregivers of patients with gynecologic cancer and correlates patients' symptom burden. This research was planned as a descriptive, cross-sectional and correlation study between May and December 2010, using a sample of 338 patient and family caregivers of gynecologic cancer patients. The results of this study show that family caregivers of patient with gynecologic cancer are at risk for hopelessness and strain. The strongest positive correlation was found between strain and hopelessness ($r= 0.23$, $p < 0.004$). Patients reported various problems with their chemotherapy experiences, including nausea, feeling weak, mouth problems, and hair loss. Some characteristics were significant predictors of the caregiver's strain and hopelessness such as age, gender, education, income level, had a child, caregiving duration, cancer type, stage of cancer, chemotherapy cycles, length of disease, caregiving hours, level of personal and social support, knowledge about diseases, other caregiving responsibilities, and patient's symptoms ($p < 0.05$). It is our hope that this study will inform oncologists, oncology nurses and mental health workers about the assessment and treatment options for strain and hopelessness in family caregiver. The findings provide a base for future research.

Keywords: Family Caregiver, Caregiver strain, Hopelessness, Gynecologic cancer, Chemotherapy

ÖZET

Kemoterapi Alan Jinekolojik Kanserli Hastaların Bakım Verici Ailelerinde Zorlanma ve Umutsuzluk

Bu çalışma jinekolojik kanserli hastaların bakım vericilerinde zorlanma ile umutsuzluk düzeylerini ve hasta semptomları ile ilişkisini araştırmak amacıyla yapılmıştır. Çalışma Mayıs-Aralık 2010 tarihleri arasında tanımlayıcı, kesitsel ve korelasyon araştırması olarak planlanmıştır. Örnekleme 338 jinekolojik kanserli birey ve bakım vericileri oluşturmuştur. Çalışmanın sonucunda jinekolojik kanserli birey ve bakımvericilerin umutsuzluk ve zorlanma açısından risk altında oldukları belirlenmiştir. Umutsuzluk ve zorlanma arasında pozitif yönde güçlü bir ilişki saptanmıştır ($r= 0.23$, $p < 0.004$). Hastalar kemoterapiye bağlı olarak mukozit, güçsüzlük, saç kaybı ve bulantı gibi çeşitli sorunlar yaşamışlardır. Bakım vericilerin umutsuzluk ve zorlanma yaşamalarını etkileyen belirleyiciler; yaş, cinsiyet, eğitim, gelir seviyesi, çocuk sahibi olma, bakım vericiliğin süresi, günlük bakım saati, hastasının tanısı, hastalığın evresi, yaşadığı semptomlar, tanı aldığı süre, kemoterapi siklusu, kişisel ve sosyal destek kaynakları, hastalık hakkında bilgi sahibi olma ve bakım vericinin diğer sorumluluklarının varlığı gibi durumlardır ($p < 0.05$). Bu çalışmanın onkolog, onkoloji hemşiresi ve ruh sağlığı çalışanlarına bakım vericilerde zorlanma ve umutsuzluk düzeyleri hakkında bilgi sağlayacağını ümit ediyoruz. Çalışmanın bulguları daha sonraki çalışmalara temel oluşturacaktır.

Anahtar Kelimeler: Aile bakımverici, Bakımvericide zorlanma, Umutsuzluk, Jinekolojik kanser, Kemoterapi

INTRODUCTION

The American Cancer Society estimates that more than 1.5 million new cases of cancer will be diagnosed this year.¹ The burden of providing care for the more than one million American patients with newly diagnosed cancer falls increasingly upon families.^{2,3} Cancer continues to be one of the leading causes of death in the Turkey.⁴ Although there is extensive literature on symptoms experienced by patients undergoing chemotherapy, there is a paucity of data on symptom burden and their impact on family caregivers' (FCs) strain.⁵ Cancer is a clinical entity that affects not only the patient's life but also the life of their FCs strains. The care of patients suffering from cancer is not limited in the hospital setting.^{6,7}

From the time of Nightingale forward, the family has been recognized by many as the most important social context in which health and illness occur, with the family being responsible for providing an environment to support the health and well-being of its members.⁸ Likewise, the health of an individual affects the health and development of individual family members and of the family as a whole.^{9,10} Because of the negative burden of care FCs are defined as at risk population or silent patient. Therefore cancer is called a family disease.¹¹

According to the most recent reports of the Turkish cancer registry, gynecologic cancers are currently the most common female cancer after breast cancer, makes it one of the most common health conditions requiring FCs support.⁴ Gynecologic malignancies in particular may intensify emotional and physical stressors by impinging on a woman's ability to bear children, altering her sense of femininity, and affecting her sexuality.^{12,13} FCs are the primary source of support for these patients during treatment.¹⁴ Studies have shown that caring for a patient with cancer has rewards such as satisfaction, closeness with the cancer patient, and a sense of fulfilling an obligation.¹⁵ Positive and negative aspects of caregiving are associated with psychological well-being and the caregiver's willingness to continue providing care.¹⁴ Caregiver strain is typically operationalized as caregiver hopelessness.¹⁶ Hope may provide a stress-buffering effect for caregivers. Higher levels of hope are associated with lower psychological distress and improved well-being for FCs. Despite the recent research directed toward the role of FCs

in cancer care, there have been few descriptions of the role of caregivers¹⁷. Whereas, cancer caregiving has also received relatively little attention in our country.¹³ Finally, attention to caregiver well being remains an area worthy of investigation which is important for both the caregivers themselves and the patients under their care.¹⁸

The aim of the study was to explore patient's symptom burden of patients and investigate their relationships with strain and hopelessness among FCs.

MATERIALS AND METHODS

Sample and Setting

This research was conducted as a descriptive, cross-sectional study of 338 patients with gynecologic cancer and 338 their FCs were enrolled in a Private University Hospital Gyneco-oncologic Outpatient Chemotherapy Unit in Ankara-Turkey. At least 500 new adult patients present at the Gynecology Unit with a gynecologic cancer diagnosis each year. All participant completed the Patient-Caregiver Information Form, the Caregiver Strain Scale (CSS), the Beck Hopelessness Scale (BHS), and the Chemotherapy Symptom Assessment Scale (C-SAS).

The face to face interviews were approximately 20-30 min each. Eligibility criteria for patients were: (a) 18 years or older, diagnosed with gynecologic cancer, (b) patients had to be receiving chemotherapy (at least two cycles), (c) can read and write in Turkish, (d) agree to participate in the research. Eligibility criteria for caregivers included either currently (within the past 3 months, (a) took main responsibility for patient care as family member (providing unpaid care); (b) were identified as his/her primary caregiver by the patient; (c) were over 18 years of age; and (d) understood the purpose of the study. A patient or a caregiver with a history of other neurologic conditions that affect cognition (e.g., stroke, traumatic brain injury) or serious mental illness (e.g., schizophrenia, major depression) were excluded from this study.

Ethical considerations: This study was approved by Institutional Review Board. In addition during the data collection phase each patient and their FCs were was informed by a written document that par-

ticipation in the study was voluntary and their privacy would be strictly protected.

Instruments

Patient Information Form: This form was developed by the researchers and contained questions directed at determining the patient's sociodemographic characteristics (age, marital status, whether they had a child, educational level, employment status, perceived economic status, whether or not they had health insurance), their status of knowing about gynecologic cancer (having information about diseases, source of information about gynecologic cancer); medical characteristics; cancer type, length of disease, recurrency, therapy style. Information concerning patients' treatment was acquired from the medical records, whereas physicians recorded their clinical condition.

Caregiver Information Form: This form was developed by the researchers and contained questions directed at determining the patient's sociodemographic characteristics (age, sex, marital status, whether they had a child, educational level, employment status, perceived economic status, whether or not they had health insurance); caregiver specific variables (questions related to such items as periods of caregiving experiences, duration of caregiving, hours of care per day, relation of caregiver to patient).

Beck Hopelessness Scale (BHS): This tool was developed by Beck, Lester & Trexler (1974) and the Turkish adaptation was done by Durak & Palabiyik (1994).^{19,20} The BHS assesses the general inclination in the participants toward pessimism and negative expectancies about the present and future an individual perceived during the past week. The hopelessness construct is a factor in many mental disorders. This self-report questionnaire consists of 20 true-false items. Higher total scores indicate a greater level of hopelessness. The range of the total scores of the BHS is between 0-20, cut-off (≥ 8). The Cronbach's alphas were 0.93 in original study, in the Turkish version was 0.83, in the present study were 0.85.

Caregiver Strain Scale (CSS): This tool was developed by Robinson (1983), and the Turkish adaptation was done by Ugur and Fadiloglu (2006).^{21,22} CSS is a tool that can be used to quickly identify families with potential caregiving concerns. CSS

helps to determine the level of strain a caregiver is experiencing. It is a 13-question tool that measures strain related to care provision, cut-off (≥ 7). There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time. Positive responses to seven or more items on the index indicate a greater level of strain. This instrument can be used to assess individuals of any age who have assumed the role of caregiver for an older adult. The higher the score, the higher the level of caregiver strain. Internal consistency reliability is high ($\alpha = 0.86$).

Chemotherapy Symptom Assessment Scale (C-SAS): This tool was developed by Brown, et al. and the Turkish adaptation was done by Aslan et al.^{7,23} The C-SAS contains 24 questions for the routine assessment including the psychological domain of symptoms experienced by patients receiving chemotherapy. Participants were asked, "Have you experienced any of the following (listed) symptoms over the last week?" (0= no, 1= yes), and if so, "How severe was the symptom?" (1= mild, 2= moderate, 3= severe) and, "How much did the symptom bother you?" (1= not at all, 2= a little, 3= quite a bit, 4= very much). For this study, one item (relating to nausea following treatment) was dropped, reducing the scale to 23 items. The C-SAS shows acceptable levels of validity and reliability (Cronbach's α , 0.75), as well as responsiveness to clinical change.

Statistical Analysis: Data analysis was performed with SPSS version 15.0 for Windows (SPSS Inc, Chicago, Illinois), the significance level was set at $p \leq 0.05$. In a study performed by Aslan et al., chemotherapy toxicity observation rate was determined to be 70 % after the treatment. When 10 % change was foreseen in this rate, minimum event number was determined to be 282 with $\alpha = 0,05$ bias share, $\beta = 0,2$ ($1 - \beta = 0,8$ power) and Type= II error. From this point, the samples of the study consisted of patients and their relatives accepted to be included in the study between May - December 2010 (11 patient were not interested in the study, 3 patients did not write the study consent form and the remaining 338 patients [96%]).

Demographic information was characterized using frequencies and percentages. Descriptive statistics, including mean, and standard deviation (SD), were

Table 1. Sociodemographic Characteristics of FCs-Patients and CSS-BHS Scores of FCs

Variables	Patient (n=338) N (%)	FCs (n=338)	BHS 5.6 ± 4.3 (Mean ± SD)	CSS 6.5 ± 1.2 (Mean ± SD)
Marital status				
Married	284 (84.0)	205 (73.9)	5.5±4.4	7.8±3.1
Single or divorced	54 (16.0)	133 (39.1)	5.9±4.9	6.9±3.2
			t=0.876, p=0.261	t=0.118, p=0.254
Education				
Middle	178 (52.7)	56 (16.6)	7.0±3.5	8.9±3.6
≥ High school	160 (47.3)	282 (83.4)	4.1±4.8	6.7±3.3
			t=5.562, p=0.002 ^a	t=3.46, p=0.01 a
Employment				
Employed	68 (20.1)	157 (46.4)	6.6±4.3	7.6±3.0
Unemployed	270 (79.9)	181 (53.6)	5.0±3.9	6.9±4.1
			t=0.933, p=0.319	t=0.166, p=0.112
Income				
Poor	54 (16.0)	27 (8.0)	7.1±5.2	9.9 ±5.6
Middle	162 (47.9)	146 (43.1)	5.5±4.5	7.4 ±4.2
High	122 (36.1)	165 (48.9)	4.2±5.4	6.4 ±5.8
			F=0.329, p=0.006 ^a	F=3.213, p=0.008 ^a

^ap< .05

obtained to describe the sociodemographic, disease-specific variables, CSS and BHS scores for patients and FCs. The validity of the said data to normal dispersion was tested via Kolmogorov smirnov test while Student t test was utilized for the symptom scores having shown a normal dispersion throughout the comparison of the said scores as per the variables under two categories, one-way ANOVA test was utilized for the comparison of the symptom scores as per the variables under more than two categories. The relationship between patient symptom burden and CSS-BHS score for FCs was assessed by Pearson's correlation.

RESULTS

Description of Patients: The 338 patients had a mean age of 56.1±11.4 years (range= 24-80). They were 84% married (n= 284), 52.7% were middle school graduates (n= 178), 79.9% were unemployed at the time of the study (n= 270), 47.9% were middle household income (Table 1). All over patients had health insurance.

When medical characteristics are considered; 33.1% of the patients had ovarian cancer; 30.2% had cancer of the endometrium and 27.8% had cervix, 77.6% had no recurrence. Most came into the

study with a diagnosis of metastatic cancer (48.8%), of the patients 65.8% was underwent only CT, 62.1% received < 6 CT cycles, 71% did not have a chronic illness experience (Table 2). The mean time since gynecologic cancer diagnosis was 55.3 months from 4 to 150 months.

Description of Caregivers: The 338 FCs had a mean age of 42.3±10.3 years (22-72). They were 71% female (n= 240); 73.9% were married (n= 205), 83.4% were high school graduates (n= 282), 53.6% were unemployed (n= 181), and 48.9% were high household income (Table 1-2). All patients had health insurance.

The mean duration caregiving was 54.1 months. Average hours of caregiving per day were 16.8, with a range from 4 to 24 hours. According to the findings obtained in this research the overwhelming majority of the participating (82.8%) in the research had adequate information about gynecologic cancer (the primary sources of this information were health care personnel and television/radio). Daughters- and sons-in-law made up 57.2% of FCs; spouses 26.6% were the next most frequent relationship to the patient (Table 3). FCs were most likely to provide caregiving activity; dressing-bathing (88.4%), transportation (72.5%), managing fi-

Table 2. Medical Characteristics and CSS-BHS Scores of Patients (n=338)

Medical Variables	Patient N %	CSS (6.5 ± 1.2) (X ± SD)	BHS (5.6 ± 4.3) (X ± SD)
Lenght of diagnosis (mth)			
< 6	135 (39.9)	7.1±3.1	5.3 ± 4.9
≥ 6	203 (60.1)	8.6±1.6	7.6±7.5
		F=3.46, p=0.020	t=3.37, p=0.002 ^a
Cancer type			
Cervix	94 (27.8)	8.9±2.1	12.4 ± 7.5
Endometrial	102 (30.2)	6.5±2.5	10.5 ± 6.7
Ovarian	112 (33.1)	6.3±3.6	8.5± 5.9
Other (vulvar, vaginal)	30 (8.9)	5.5±4.0	6.6±4.2
		t= 5.13, p= 0.001 ^a	F=4.68, p=0.002 ^a
Cancer stage			
Localized	40 (11.8)	5.9±2.3	4.8± 4,9
Localized metastatic	165 (48.8)	6.5±2.2	5.2±4,9
Advanced metastatic	133 (39.4)	7.1±1.9	7.9 ±4.8
		t= 4.03, p= 0.04 ^a	F=3.37, p=0.005 ^a
Therapy type			
Chemotherapy	221 (65.8)	6.5±3.2	6.4±6,5
Chemotherapy+Radiotherapy	117 (34.2)	6.3±3.6	5,1±5,8
		t= 1.03, p= 0.06	t=1.39, p=0.05
Number of CT cycles			
< 6	210 (62.1)	6.5±2.1	6.4±4,5
≥ 6	128 (37.9)	9.3±2.2	8,4±5,2
		t= 6.27, p=0.001 ^a	t=6.22, p=0.001 ^a
Recurrence			
Yes	78 (22.4)	9.5±3.1	5,0±3,9
No	260 (77.6)	6.5±2.5	9,6±9,3
		t=6.59, p=0.001 ^a	t=5.83, p=0.000 ^a
Comorbidite ^b			
Yes	98 (29.9)	6.9±2.3	8.2 ±4.6
No 240 (71.0)	7.0±2.2	7.6±4.0	
		t= 0.28, p=0.082	t=0.13, p=0.873

^a p <.05; ^b Comorbidities; hypertension, diabetes mellitus, thyroid disorders

nances or bills (66.3%), preparing meals (75%), feeding (82.4%), giving pills, medications, or injections (77.6%), shopping (98.7%). The psychological, financial and sociologic changes, despite not being included in the table, were examined and it was seen that 94% had problems in the human relations, 88% has problems in the domestic life, 72% in following the daily actions, 78% in the cultural and social activities, 69% in the financial state, 64 % in the work life and family relations (34%).

Findigs related to caregivers' strain and hopelessness; Mean scores for caregiver hopelessness level, and caregiver starin presented in Table 1. The FCs' mean CSS score was 6.5 ±1.2, and the mean BHS score was 5.6±4.3, the FCs in this study experien-

ced a mild level of hopelessness (Thirty-three percent of FCs scored above the BHS cut-off (≥ 8) for hopelessness). BHS and CSS scores were compared with "consequences" had a positive relationship with each other (r= 0.230, p> 0.004).

The BHS-CSS scores of FCs were significantly and positively correlated with socio-demographic-medical variables such as age, sex, education, employment status, income level (Table 1-2), caregiving duration, lenght of illness, caregiving duration, hours of care in a day, number of CT cycles, stage of cancer and cancer type (Table 2). The impact on CSS score was highest for female caregivers, elderly caregivers, caregivers of patients with ovarian cancer, ≥ 6 CT cycles and caregivers of patients

Table 3. General Characteristics and CSS-BHS Scores of FCs (n=338)

Variables	FCs		CSS	BHS
	N	(%)	(X ± SD)	(X ± SD)
Age, y				
20-39	56	(16.6)	7.7±3.1	5.7±3.2
40-59	185	(54.7)	8.6±1.6	6.9±5.6
≥ 60	97	(28.7)	9.8±1.2	7.8±6.4
			F=3.46, p=0.020 ^a	F=2.97, p=0.01 ^a
Sex				
Female	240	(71.0)	8.9±2.1	8.3±4.8
Male	98	(29.0)	6.5±2.5	5.5±4.8
			t= 5.13, p= 0.001 ^a	t=5.61, p=0.001 ^a
Had a child				
Yes	238	(70.4)	7.3±5.0	7.3±5.0
No	100	(29.6)	5.5±4.7	5.5±4.7
			t=0.763, p=0.000 ^a	t=0.763, p=0.000 ^a
Adequate knowledge about diseases				
Yes	280	(82.8)	6.9±2.3	5.6±4.4
No	58	(17.2)	8.0±2.2	7.1±4.2
			t=0.693, p=0.071 ^a	t=4.22, p=0.034 ^a
Caregiving duration (mth)				
< 6	85	(25.0)	5.0±1.0	9.7 ±6.6
≥ 6	223	(75.0)	7.2±1.6	12.8± 4.6
			t=3.34, p=0.04 ^a	t=6.23, p=0.000 ^a
Caregiving hours (day)				
< 6	55	(16.3)	4.3±2.0	8.7±5.2
≥ 6	283	(83.7)	7.6±1.3	12.6±5.8
			t=7.34, p=0.001 ^a	t=8.55, p=0.000 ^a
Personal and social support				
Yes	103	(30.5)	6.1±1.3	10.4±4.5
No	135	(69.5)	7.3±5.3	8.0±6.5
			t=5.91, p=0.02 ^a	t=4.03, p=0.008 ^a
Other caregiving responsibilities				
Yes	87	(26.4)	6.7±1.3	8.5±4.6
No	281	(73.6)	6.4±3.8	8.2±6.3
			t=0.34, p=0.524	t=1.38, =0.066

^a p< .05

with advanced stage disease. Consistent with this, the levels of BHS scores increased. FCs of patients with the shortest time to diagnosis had the lowest levels of hopelessness (p< 0.05). Poor economic status were found to have higher levels of hopelessness (p< 0.05). We found that the high level of CSS and BHC scores can exist in the presence of lower levels of patient education (p< 0.05). Longer caregiving duration, more cycles of CT and more hours of care in a day are associated with CSS-BHS scores of FCs (p< 0.05). Unemployed caregivers reported greater levels of CSS and BHS scores than employed FCs, but there were no statistically significant

differences (p> 0.05) (Table 1).

Related chemotherapy toxicity; Maximum symptom number in a person was 19, there was not a case where symptom is not seen. Impact of side effects and consequences of cancer were measured by prevalence, severity and bother associated with each symptom. Patients reported nausea (74.6%), hair loss (92.8%), mouth/throat problems (76.9%), feeling weak (88.7%), and changes to appetite (76.9%) as the most prevalent physical symptoms, with nausea (50%), bleeding/bruising (33.3%), and feeling unusually tired (33.3%) as their most severe symptoms. The three most bothersome physical

Table 4. Prevalence of symptoms, symptom severity, symptom bother and CSS-BHS Score of patients

C-SAS ^c (3-19)	Bother Severity		Prevalance		CSS		BHA	
	(%) ^a	(%) ^a	(%)	(X±SD)	(X ±SD)	(rho)	(X ±SD)	(rho)
Nausea	50.0	40.0	74.6	2.0±0.2	13.1±4.3 ^b	r= 0.18	10.0±3.9 ^b	r= 0.20
Vomiting	23.1	22.2	42.6	2.0±0.3	7.4±1.8 ^b	r=0.20	6.4±2.0 ^b	r= 0.19
Constipation	21.7	29.7	39.6	2.0±0.4	6.0±1.7 ^b	r=0.28	5.0±1.7 ^b	r= 0.18
Diarrhea	11.1	11.1	17.7	1.0±0.5	7.8±2.6	r=0.11	6.2±2.4	r= 0.10
Pain	16.7	15.0	29.2	2.0±0.2	6.4±1.1 ^b	r=0.28	6.1±1.3 ^b	r= 0.18
Shortness of breath	30.8	28.6	18.9	2.0±0.4	7.8±2.6 ^b	r=0.17	6.2±2.4 ^b	r= 0.18
Signs of infection	12.5	12.5	25.1	1.0±0.3	7.0±2.3	r=0.09	6.8±1.9	r= 0.03
Bleeding/bruising	33.3	25.0	10.3	2.0±0.2	6.0±2.1	r=0.04	5.4±1.7	r= 0.01
Pins and numbness	18.2	17.6	44.6	2.0±0.5	5.4±2.1	r=0.01	7.4±2.9	r= 0.01
Skin- nail problems	8.6	8.4	48.8	1.0±0.3	7.7±1.7	r=0.14	6.3±2.0	r= 0.08
Hair loss	20.7	22.0	92.8	2.0±0.2	8.3±2.1	r=0.03	6.9±1.5	r= 0.02
Mouth problems	22.0	22.0	76.9	2.0±0.2	9.2±2.8 ^b	r=0.25	11.9±4.6 ^b	r= 0.17
Changes to appetite	19.2	19.2	78.1	1.0±0.3	9.9±4.0 ^b	r=0.20	12.±4.3 ^b	r= 0.24
Weight loss/gain	10.6	13.6	71.9	2.0±0.4	6.4±2.8	r=0.05	7.4±2.4	r= 0.01
Eye problems	3.0	3.0	7.3	1.0±0.2	5.3±2.1	r=0.01	5.1±2.0	r= 0.01
Feeling weak	23.2	23.2	88.7	2.0±0.4	9.0±2.9 ^b	r=0.30	9.0±2.5 ^b	r= 0.29
Unusually tired	33.3	33.3	48.2	1.0±0.4	11.5±4.5 ^b	r=0.20	11.8±4.4 ^b	r= 0.33
Difficulty sleeping	6.4	6.4	47.0	1.0±0.4	6.9±2.0	r=0.10	6.7±1.9	r= 0.14
Headaches	7.1	7.1	42.0	1.0±0.2	5.5±1.8	r=0.09	5.6±1.8	r= 0.12
Anxious/worried	11.1	11.1	42.8	2.0±0.5	7.0±2.7 ^b	r=0.19	7.0±2.5 ^b	r= 0.26
Low/depressed	16.7	15.7	44.9	2.0±0.3	7.6±2.3 ^b	r=0.21	6.9±1.9 ^b	r= 0.31
Changes to sexualy	29.4	26.5	52.9	2.0±0.4	10.3±6.3 ^b	r=0.23	11.6±4.2 ^b	r=0.20
Changes to period	22.2	22.2	28.9	1.0±0.5	5.0±1.6	r=0.10	5.3±1.2	r=0.09

^a Symptom bother; very much- Symptom severity; severe,
^b p< .05; ^c= Symptom status (3-5); 22.5%, (7-9); 54.5%, (≥10);23.0%.

symptoms were bleeding/bruising (28.6%), constipation (29.7%) and nausea (40%). This study demonstrated that relationships between toxicity representations and CSS-BHS scores in gynecologic cancer patients ($p < 0.05$). To decrease BHC-CSS scores for FCs; nausea, vomiting, pain, feeling weak, unusually tired, worried, depressed, sign of infection, shortness of breath, mouth/throat problems, changes to appetite, and changes to sexual relations must decrease in the patients (Table 4).

DISCUSSION

The perceived unpredictability of the course of cancer, the fact that it is often viewed as life threatening, and that it may recur even when the patient is doing well may heighten emotional stress among FCs.¹⁵ This study focused on how patient's symptom burden and caregiver characteristics interaction affects caregiver strain and hopelessness. Greater levels of CSS-BHS were significantly associ-

ated with female gender in our study. In the study performed by Durak and Palabiyikoglu²⁰, there was not a meaningful difference between the BHS points in terms of gender difference. Torti, et al. expressed that the women caregivers had a higher level of social isolation and depression.²⁴

Using a meta-analysis of previous work, researchers found that female caregivers had poorer well being than male caregivers and greater stress and depression were found in older caregivers.²⁵ In general, educated people had a higher possibility of living skills including the skills of stress management techniques.⁵ We found that FCs with less than a high school education were more distressed than those with higher levels of education. The financial impact and hidden costs of cancer may affect caregiver burden. Neglecting their own health may refer caregivers to despair.⁶ However, Biegel, Sales and Schulz found no relations between the responsibilities of the care giver and the financial featu-

res.²⁶ In our study, caregiver's financial hardship was significantly associated with CSS-BHS scores. Limited financial resources placed FCs at risk for strain or hopelessness. This result made them think that the caregivers with low economic levels has problems in accessing the treatment and social opportunities affected the treatment process in a negative way. Pinquart and Sorensen found that better well-being was correlated with caregivers who were married.²⁵ However in a study conducted by Sherman, et al., FCs who were married to the patient had increased strain, and emotional problems.²⁷ The rate of FCs having strain and hopelessness was similar to that found in our study but there were no statistically significant differences.

Older caregivers are especially vulnerable because they may present with comorbidities, they may be living on fixed incomes, and their available social support networks may have shrunk. In addition, older caregivers of cancer patients may neglect their own health needs, have less time to exercise, forget to take their own prescription medications, and become fatigued/feeling weak from interrupted sleep. It is therefore common for caregiving by older people to lead to poor physical health, hopelessness, and strain.^{28,29} Yet another study found that coping strategies of older caregivers were fewer and less effective.^{30,31} Greater levels of CSS-BHS were significantly associated with older FCs in our study.

A hopeful attitude is important for psychological well being. In general, hopelessness can be seen the FCs due to deterioration in the physiological state, insufficiency in the social support, isolation due to disease, not being able to meet the needs during the treatment period, negative results of the patient, long treatment period, activity restrictions.³² In the study performed by Durak and Palabiyikoglu total point of BHS was 4.60 ± 4.36 ; in a study performed by Tan and Karabulutlu, minimum 4 months passed from cancer diagnosis and the BHS point average was 6.5 ± 3.6 ; in the study of Yildirim, et al. with patients without advanced cancer, BHS point average was 5.20 ± 4 .^{39,20,33,34} Previous results were parallel to that found in our study, the FCs were seen to be hopeless at the middle level.

Caregiver strain is a mood disturbance resulting from the stress of providing care, performing complex medical procedures, coping with disrupti-

ons in daily routine, and negotiating the need to provide emotional support to the patient and to other family members, which may be manifested as feelings of loneliness, isolation, fear and anxiety. Together, caregiver strain and hopelessness may be considered as a general distress response for caregivers.^{32,35} In our study, the care givers were seen to be strain at the middle level. In the literature, "difficulties in the care givers" is a term reflecting the physical, emotional, social and financial problems and undergone by the family members caring for physically or mentally ill adults. The caregiving period brings some problems such as "load" and there are also individual development emotions such as individual success, maturity without negative results.^{2,21,28,36} Pinquart and Seronsen stated that the care givers in some societies is proud of the work they do where the positive perceptions are influenced by the cultures, they felt important as they helped someone, for this reason they considered the process from a positive aspect.²⁵ In the Turkish society, care giving for the old, ill and needy people is a socially accepted concept. In our society, caring for the old by his / her children or children in law is considered to be a social and religious responsibility.³³ Even the caregivers are stated to live the feelings of being valuable and important due to caregiving. As this situation is a natural process, it is a factor mitigating the load. In general, expressing and showing the load caused by the caring work is not acceptable socially but this does not prevent the feeling of load of this work.³⁴

In our study, all FCs stated that it was took on added responsibilities for assisting with activities of daily living, such as bathing and feeding, and instrumental activities of daily living, such as shopping, managing the household finances after hospitalizations. FCs also performed nursing duties, such as changing dressings and administering medications. In other studies performed by Bart, et al., Lillius and Julkunen and Baer, et al., the FCs were detected to undergo changes in the family processes, they had to make changes in the individual programs and they had some difficulties for those reasons.^{18,37,38} The acknowledgement and recognition of these problems by oncology nurses might contribute to finding solutions in order to assist the difficult task of these individuals.⁵

Caregiving is time consuming and can lead to feelings of social isolation.¹⁴ Pinquart and Sorensen determined that the period of care giving role was also stated to be important and the caregivers and it was found that the longer he care giving period was, the greater the load got.²⁵ Kim, et al. determined in their study that as the daily caregiving period was longer, the greater the load became.⁶ Mc Clement and Chochinov determined that there was a direct relation between the period of caregiving and the caring load. Similar to the literature, in our study, we also determined that as the caregiving period got longer, the stress and hopelessness increased.¹⁷ This result was considered to be affected by the decrease in belief for the patients to get better who were in search of treatments and health for a long time.

Patients with gynecologic cancer diagnosed at an advanced stage require considerably more emotional, informative, and instrumental support from health workers.¹³ In a study FCs' strain had been found to be influenced by the cancer patient's stage.⁸ We found that, the caregivers for patients with advanced level cancer were having more difficulties which was found to be statistically meaningful.

Receiving support from others is very important during times of stress. The seeking of support from another person is a healthy and effective way of dealing with a stressful event.⁹ In the study performed by Palos, the care givers were detected to have difficulties in the caring process as the possibility of getting help from the other family members was low.²⁹ In our study, the FCs interviewed generally carried out these additional responsibilities alone, only 30.5% of the caregivers were determined to get help in the caring process. FCs with lower levels of personal and social support experienced higher levels of distress. Caregiver burden refers to a high level of stress that may be experienced by people who are caring for another person with some kind of illness.²⁸ In the study performed by Feinberg half of the caregivers cared for an old person and had difficulties. In our study 26.4% were determined to be responsible for another person who were in need of their care.² However, when the care and the presence of an additional person was compared there was not an important difference in the CSS-BHS point average.

Educating caregivers about pertinent aspects of cancer management by nurses can be accomplished through individual contact with health care professionals or through more formal educational programs.⁹ In our study, the caregivers were mostly seen to have adequate knowledge about the disease and the treatment (82.8%). The caregiver having enough knowledge about their patients were having less difficulty which was statistically meaningful. In the study performed by Awadalla, et al. similar findings were also present.^{1,2} FCs stress and coping framework has been expanded by Folkman, et al. which is a traditional stress-coping perspective. This transactional model recognizes that it is the family member's unique response to caregiving, including the family dynamics that impacts on the family member's psychological reaction.³⁹ FCs often feel unprepared, have inadequate knowledge, and receive little guidance from the oncology team for providing care to the cancer patient. Because the focus was on the patient, their own needs were neglected.^{8,14} Family members are the primary source of support for these patients, yet empirical research that documents the impact of cancer on family members is still very limited.^{2,3}

Gaps in the literature remain, however few studies are driven to examine the effects of gynecologic cancer patient and their caregiving.^{13,40} A diagnosis of gynecologic cancer frequently causes an emotional trauma to patients, which is reflected in increased feelings of vulnerability, loss of control and uncertainty. Treatment of gynecologic malignancies generally requires chemotherapy, and/or radiation therapy, both of treatment-related symptom burden which have a potential to affect life quality for patients and their caregivers. FCs have varying emotional reactions to patient symptoms, which can cause distress as the patient's health declines.⁴¹ Therefore, the interaction of CSS and HBS must be considered along with the patient symptom experience.^{22,30,32}

CONCLUSION

FCs reported various problems with their caregiving experiences, including conflict among their social roles, restrictions on activities, strain in marital and family relationships, psychological distress, and diminished physical health. As a result of,

FCs' strain and hopelessness were associated with patient's symptom burden. This association indicated that patient's symptom burden was an important results in FCs' strain and hopelessness. Therapeutic intervention programs to lessen hopelessness and strain would be required to meet the needs of FCs and their patients with gynecologic cancer undergoing chemotherapy. Particularly, gynecology nurses are key persons in contact with FCs. Future research must continue to examine the distinction between strain and hopelessness, and to continue to explore the myriad other factors that may contribute to negative caregiver outcomes for those caring for patients with gynecologic cancer. Additional qualitative studies are needed to provide information about the depth and diversity of FCs strain-hopelessness.

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