

Original Article

Evaluating the Care Burden of Caregivers of Colon Cancer Patients

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Correspondence: Gonul Yilmaz Dundar, MSc, Research assistant Bandirma Onyedi Eylul University Faculty of Health Sciences, Bandirma, Balikesir, Turkey Email: gnlylmz1903@hotmail.com**Abstract****Aims:** The study is descriptive and cross-sectional in order to evaluate the care burden of "care-giver" relatives of the patients who were diagnosed with colon cancer and underwent surgery.**Materials and Methods:** This study was conducted in the General Surgery Services of the Cerrahpasa Medical Faculty, Istanbul University. The sample consisted of "care-giver" relatives of 130 patients hospitalized in the General Surgery Services of the Cerrahpasa Medical Faculty, Istanbul University between November 2014 and June 2015, diagnosed with colon cancer, and undergoing surgery. Data were collected by the Zarit Burden Interview. The data were evaluated by using the SPSS package program.**Results:** The average age of the caregivers was 46 years. The majority of the caregivers were female, married, and primary school graduate. 48.5% of them were spouse and 82.3% of the caregivers provided constantly care, and had difficulties mostly in hygiene practices. Mean score obtained by the caregivers from Zarit Burden Interview was 31.37 ± 8.92 (7-63).**Conclusion:** The caregivers of patients with colon cancer had moderate and severe burden. Subjects who were female, spouses, stayed in the hospital for more than one month and provided care in turns, were significantly higher.**Keywords:** Colon cancer, care burden, patient relatives**Introduction**

Colorectal cancer including colon cancer is the 3rd most common malignancy in men and 2nd most common malignancy in women according to data of International Agency for Research on Cancer (<http://globocan.iarc.fr>). Cancer statistics of Turkish Ministry of Health point out that the incidence of colon cancer is 22.8 per 100,000 in men while it is 13.8 per 100,000 in women (<https://hsgm.saglik.gov.tr/tr/haberler/324-kal%C4%B1n-ba%C4%9F%C4%B1rsak-kanseri-kolorektal-kanser.html>).

In addition to the rise in the number of individuals diagnosed with colon cancer, patient survival improves in concordance with the advances in diagnostic and therapeutic approaches, increasing the responsibility of family members providing care to colon cancer patients (Orak & Sezgin, 2015; Kitrungröter & Cohen, 2006). The presence of a cancer patient in the family causes changes in the daily routine of family members and puts them in a position where they have to adapt to the new situation. Long, chronic and life-threatening nature of the

disease, along with the fact that patient may not be able to go back to professional and social life increase the family caregiver's responsibility and alter the roles within the family (Ozturk Kaynar & Vural, 2018).

The burden of care is affected by various factors including the age of the caregiver; his/her present illnesses, relatedness to the patient and the severity of symptoms experienced by the patient. Also surgical interventions applied to individuals with colon cancer may result in either temporary or permanent colostomy. Colostomy care and related complications, altered body image, surgical site infections, diet changes and problems with sexual life can be encountered in the postoperative period (Adegboyega et al., 2017; Vural, Sutsunbuloglu & Selimen, 2016). These problems increase the patient's physical and psychosocial care needs, thus creating a bigger care burden for the caregiver. Caregivers perform many duties including physical, social and emotional support, setting up outpatient clinic appointments, helping with daily activities at home and providing stoma care products, performing or helping with stoma care

(McMullen et al., 2014). Family members who take primary caregiving responsibility experience difficulties due to daily life activities being negatively affected and physical, emotional, psychological, social, economic and professional problems (Turkoglu & Kilic, 2012; Yildiz, Dedeli & Cinar Pakyuz, 2017).

When caring for a colon cancer patient, nurses, involved in the multidisciplinary health care team, should handle the patient and their family as a whole. Determining the care burden of caregivers of patients is considered to guide stating the needs of caregivers, meeting these needs in advance and planning appropriate nursing interventions to decrease the care burden (Ozturk Kaynar & Vural, 2018). The aim of this study is to investigate the care burden of caregivers of patients who underwent surgery for colon cancer

Materials and Method

This study was planned as a descriptive cross-sectional study in order to investigate the care burden of family caregivers of patients who are diagnosed with and underwent surgery for colon cancer. The study was conducted in Istanbul University Cerrahpasa Faculty of Medicine Department of General Surgery inpatient clinics between November 2014 and June 2015. The sample of the study consisted of family members who provided care for 137 patients who are admitted to Istanbul University Cerrahpasa Faculty of Medicine Department of General Surgery inpatient clinics and diagnosed with and underwent surgery for colon cancer. The sample of the study included 130 family members who fulfilled the necessary criteria and volunteered to participate in the study.

Data Collecting Tools

An information form was developed by the researcher in the light of the current literature and this was used as the data collecting tool. The information form was made of two sections. The first section included 14 questions about the age, sex, marital status, educational status, family history of colon cancer, family history of other cancers and duration of hospital stay of the caregiver family member. Zarit Caregiver Burden Scale, which was developed by Zarit, Reever and Bach-Peterson, was used in the second section.

Zarit Caregiver Burden Scale: Zarit Caregiver Burden Scale (ZCBS) was used to evaluate the care burden of caregivers in the study. Caregiver burden scale is developed by Zarit, Reever and Bach-Peterson in the USA in 1980 with the help of relevant studies, caregivers and the clinical

experience of caregivers. The scale is used to evaluate the stress of the ones who provide care for the needy or elderly. It includes questions about health, social and personal life, financial situation, emotional well-being and interpersonal relations. Every item is scored from 0 to 4 as a Likert-type scale, with 0=never 1=rarely 2=sometimes 3=frequently and 4=nearly always. Total score obtained from all items represents care burden (Ozer, et al., 2012). Ozer and colleagues performed validity and reliability testing of Zarit Caregiver Burden Scale in medical and surgical fields and found that 18 out of 22 items were valid. The maximum score that can be obtained from the scale is 72 while the minimum is 0. The items in the scale are mostly related to social and emotional field and higher scale scores indicate higher care burden and trouble experienced. Cronbach alpha reliability coefficient of the scale was found to be 0.83. Cronbach alpha reliability coefficient in this study is 0.701.

Data Analysis: SPSS (Statistical Package for Social Sciences) for Windows 23 was used for statistical analysis of data acquired in the study. Descriptive statistical methods (mean, median, number, percentage) were used when evaluating study data. Independent samples t test and ANOVA (variance) analyses were used for group comparisons.

Ethics of the Study: Principle of volunteering was prioritized in the study. Informed consent forms were provided to caregivers and those who agreed to participate in the study both in verbal and written ways were included in the study. Ethics committee approval was obtained from Istanbul University Cerrahpasa Faculty of Medicine Ethics Committee (ethics committee no: A-19). Institutional permit was obtained from Istanbul University Cerrahpasa Faculty of Medicine Department of General Surgery.

Results

Descriptive characteristics and mean ZCBS scores of 130 family caregivers included in the study are summarized in Table 1. Mean age of caregivers was 46.17 ± 10.97 . Out of 130 caregivers, 66.9% were female, 81.5% were married, 50.8% graduated from primary school and 48.5% had well economic status. When descriptive characteristics of the caregivers were compared with ZCBS scores, it was observed that age, marital status, educational status and economic status did not cause any significant difference in ZCBS scores. However, mean ZCBS scores of women (32.80 ± 9.09) were

significantly higher than mean ZCBS scores of men (28.47 ± 7.90) ($t: 2.671$; $p < 0.05$) (Table 1). A 48.5% of the subjects were spouses, 21.5% had a family history of colon cancer and 57.1% of those 28 subjects had a first degree relative with colon cancer. Also, 57.7% of subjects were found to have a family history of malignancies other than colon cancer. When family history characteristics were compared with ZCBS scores, family history of colon cancer and relatedness degree had no significant difference. However, mean ZCBS scores of subjects showed a statistically significant difference with regards to relatedness to the patient ($F: 21.042$; $p < 0.001$). This difference was observed in all groups. The subjects that had the lowest care burden were spouses (28.41 ± 7.55). As the caregiver's degree of relatedness to the patient grew distant, the care burden was found to increase. The mean ZCBS scores of subjects with a family history of malignancies other than colon cancer (33.16 ± 8.89) was significantly higher than

caregivers with no family history of cancer (28.93 ± 8.44) ($t: 2.762$; $p < 0.05$) (Table 2). Out of 130 patients that underwent surgical intervention, 61.5% had a stoma, 47.7% hospitalized for less than 15 days, 82.3% were continuously accompanied by family members who experienced the most difficulty in hygiene practices during patient care. There was no significant difference between ZCBS scores, difficulties experienced during care process and the presence of a stoma. However, a significant difference was observed between the duration of stay in the hospital and the mean ZCBS scores of subjects ($F: 5.975$; $p < 0.05$). The subjects whose patients stayed in the hospital for more than a month had the highest care burden (38.06 ± 10.39). Mean ZCBS scores of subjects who continuously accompanied their patients (30.60 ± 9.05) was significantly lower than mean scores of subjects who alternated in accompanying their patients (34.96 ± 7.47) ($t: 2.156$; $p < 0.05$) (Table 3).

Table 1: Descriptive Characteristics of Caregivers and Mean Scores from Zarit Care Burden Scale

Variables	n	%	Mean \pm SD	t/F	p
Age				0,613 ^a	0,690
15-25	5	3.8	33.40 \pm 3.29		
26-35	17	13.1	33.06 \pm 8.50		
36-45	32	24.6	32.72 \pm 7.54		
46-55	55	42.3	29.98 \pm 10.02		
56-65	17	13.1	31.47 \pm 8.90		
66-75	4	3.1	29.50 \pm 11.09		
Gender				2.671^b	0.009*
Female	87	66.9	32.80 \pm 9.09		
Male	43	33.1	28.47 \pm 7.90		
Marital status				0.588 ^b	0.560
Married	106	81.5	31.15 \pm 8.96		
Single	24	18.5	32.33 \pm 8.88		
Education				1.319 ^a	0.271
Primary	66	50.8	31.73 \pm 9.19		
Secondary	43	33.1	29.79 \pm 7.69		
University	21	16.1	33.48 \pm 10.20		
Income				0.691 ^a	0.503
Good	63	48.5	32.13 \pm 10.36		
Equal	28	21.5	31.57 \pm 7.20		
Bad	39	30.0	30.00 \pm 7.44		

*= $p < 0.05$; a=ANOVA(Variance) Analysis, b = Independent Sample t Test

Table 2: Distribution of Caregivers According to Family History Characteristics and Mean Scores from Zarit Care Burden Scale

Variables	n	%	Mean±SD	t/F	p
Caregiver/patient family relationship				21.042 ^a	<0.001*
Spouse	63	48.5	28.41±7.55		
First Degree Relative	61	46.9	32.67±7.51		
Other	6	4.6	49.17±12.58		
Family History of Colon Cancer				0.135 ^b	0.893
Yes	28	21.5	31.57±6.95		
No	102	78.5	31.31±9.42		
Proximity to People With Bowel Cancer in the Family (n=28)				1.864 ^b	0.076
First Degree Relative	16	57.1	29.50±6.18		
Second Degree Relative	12	42.9	34.33±7.22		
The Presence of Cancer in the Family Other than Colon Cancer				2.762 ^b	0.007*
Yes	75	57.7	33.16±8.89		
No	55	42.3	28.93±8.44		
Proximity to Patients Diagnosed with Cancer (n=75)				1.427 ^b	0.166
First Degree Relative	59	78.7	32.44±9.00		
Second Degree Relative	16	21.3	35.81±8.21		

*=p<0.05; a=ANOVA(Variance) Analysis, b = Independent Sample t Test

Table 3: Distribution of Caregivers According to Treatment and Disease Process of the Patient and Means Scores from Zarit Care Burden Scale

Variables	n	%	Mean±SD	t/F	p
Stoma				0.414 ^b	0.680
Yes	80	61.5	31.11±9.31		
No	50	38.5	31.78±8.34		
Length of Hospital Stay				5.975 ^a	0.003*
less than 15 days	62	47.7	30.13±9.92		
15 to 30 days	51	39.2	30.65±5.75		
More than a month	17	13.1	38.06±10.39		
Accompanying Shape				2.156 ^b	0.033*
Continuously	107	82.3	30.60±9.05		
Alternated	23	17.7	34.96±7.47		
Difficulties Experienced in the Care Process				0.842 ^a	0.473
I have no difficulty in anything	16	12.3	29.06±13.51		
I have difficulty in hygiene practices	75	57.7	31.88±8.66		
I'm having trouble with psychological support	35	26.9	30.80±7.18		
Other	4	3.1	36.00±2.45		

*=p<0.05; a=ANOVA(Variance) Analysis, b = Independent Sample t Test

Discussion

Cancer is currently one of the most important health problems. Colon cancer is reported to be one of the most common among all cancer types. Also, colorectal cancer ranks the most frequent among gastrointestinal system malignancies. Family members who provide care for colon cancer patients experience problems about care during the disease process (Alici, Izmirli & Dogan, 2006; Wilkes, 2010). Women caring for elderly in Işık and Erci's (2018) study and caregiving women in Akgun Sahin's (2014) study were found to have significantly higher mean ZCBS scores. In our study, mean ZCBS scores of female caregivers (32.80 ± 9.09) were significantly higher than male caregivers (28.47 ± 7.90) ($p < 0.05$). Similar to the literature findings, the results of the current study indicate that women caregivers take up caregiving responsibility either voluntarily or mandatorily, women are more sensitive and they have the ability to establish closer and strong relationships (Table 1). When marital status of caregivers and their mean ZCBS scores were compared, Zaybak et al (2012) performed a study for determining the care burden of individuals providing care for bed-bound patients and found that single caregivers have higher care burden. Similarly, mean ZCBS scores of singles were higher than the married. However, Chindaprasirt et al (2014) found no significant association between marital status and care burden (Table 1).

In the present study, we found that almost all individuals who provide primary care for colon cancer patients were spouses and first degree relatives and spouses had the lowest care burden among caregivers. Also, as the caregiver's degree of relatedness to the patient grew distant, the care burden was found to increase. Selen and Kav (2014) observed that spouses have significantly lower care burden scores than other family members. Selcuk Tosun et al (2015) also found that care burden score increases according to the degree of relatedness and this was statistically significant. It may be reasonable to assume that caregivers who are blood-relatives to the patient are more attached to family values and more sensitive towards their patients (Table 2). Chronic diseases that cause constant and permanent disabilities and require long-term monitoring, control and care bring an extra burden to the family of the sick individual (Wilson et al., 2005). In their study, Tasdelen and Ates (2012) found that 26% of the caregivers had another

individual that required care in their family other than the patient. Cetinkaya and Karakovan (2012) showed that caring for another individual other than the cared patient increases both physical and emotional burden. In the present study, more than half of the caregivers had another family member with a malignancy other than bowel cancer and mean ZCBS score of these caregivers (33.26 ± 8.89) was significantly higher than caregivers with no other family history of cancer ($p: 0.007$) (Table 2).

Colostomy is an artificial opening where the colon is diverted to the abdominal wall. Patients with stoma encounter many physiological, psychological and social problems and these problems negatively affect the quality of life of both the patient and their family (Agcakaya, 2015; Aksoy & Cavdar, 2015). Ozturk Kaynar and Vural (2018) evaluated care burden of caregivers of colorectal cancer patients and found that care burden of individuals caring for a patient with a stoma is higher than the burden of individuals caring for a patient without a stoma. In their study where the care burden of individuals providing care for patients with a permanent colostomy, Erek Kazan et al (2014) found that mean ZCBS score of family members indicate near-moderate care burden and had no statistical significance. Near-moderate care burden, where it is expected to be high, may be interpreted as caregivers not being much included to stoma care during hospital stay and care burden not being increased for caregivers because stoma care is performed with the help of stoma therapy nurse. Time spent caring is one of the factors that affect the care burden (Garlo, 2010; Pinguart and Sorensen, 2007). Yuksel et al (2007) performed a study with the caregivers of Parkinson's patients and found that time spent caring had a positive correlation with care burden. Hsu et al (2017) also found that as time spent caring increased, mean care burden increased. Similarly, in the present study mean ZCBS scores increased as the duration of hospital stay increased (Table 3).

In their study where the care burden of individuals caring for dementia patients were evaluated, Cetinkaya and Karakovan (2012) revealed that more than half of the caregivers share the care with other family members and try to reduce the burden by sharing. Ozmen's study (2015) graded mean ZCBS scores of continuous caregivers as moderate burden. In this study, mean ZCBS scores of caregivers who

continuously accompany their patients (30.60±9.05) is significantly lower than caregivers who alternated in accompanying their patients (34.96±7.47) (t: 2.156; p<0.05). This finding indicate that continuous caregivers undertake this as their duty and consider care as a daily work, while alternating care givers consider caring as an obligation and therefore have higher care burden.

In conclusion, in this study that evaluated care burden of individuals caring for colorectal cancer patients, we found the care burden to be moderate. In the light of our findings, it is recommended that nurses should give education to patients and caregivers, provide motivation, encourage, and support stoma care in order to decrease the care burden of caregivers of patients who underwent surgery for colon cancer. An atmosphere of trust where the caregivers can express their emotions and thought comfortably should be ensured; new caregivers should be informed according to their information and technical needs and psychological support should be provided. Randomized controlled studies that assess the efficiency of interventions for decreasing the burden of caregivers of colon cancer patients are suggested.

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