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RESEARCH ARTICLE

Assessment of the Caregiver Burden of Caregivers of Colorectal Cancer Patients

Kolorektal Kanserli Hastalara Bakım Verenlerin Bakım Yükünün İncelenmesi

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ABSTRACT

Aim: To examine caregiver burden of caregivers of patients with colorectal cancer.

Method: This is a prospective, cross-sectional, descriptive study. The sample consisted of 162 patients who underwent colorectal cancer surgery between January 1 and June 30, 2015 in the General Surgery ward of Dokuz Eylül University Hospital. Data were collected using the Caregiver Strain Index (CSI) and the Your Reactions to Helping Your Family Member scale (RHFM), which is a component of the Family Care Inventory. Descriptive statistics, Mann-Whitney U, Kruskal-Wallis test, and Pearson correlation analysis were used in data analysis.

Results: The mean age of the patients was 58.5±12.7 years and the mean age of the caregivers was 51.8±10.8 years. Of the patients, 51.2% were male, 38.9% (n=63) underwent low anterior resection, and 66.7% had a stoma. Fifty-eight percent of the caregivers were female. The caregivers' mean CSI score was 3.61±3.52 and mean RHFM score was 50.50±9.78. There were statistically significant correlations between caregiving burden and patients' age and stoma status ($p<0.05$). Patient gender and surgery type did not affect caregiver burden ($p>0.05$). Caregiver age, duration of care (days), and receiving caregiving assistance were associated with caregiver burden ($p<0.05$). However, the caregivers' gender, marital status, and education level did not affect caregiver burden ($p>0.05$). Presence of stoma, caregiver gender, duration of care, and caregiver relationship to patient were found to affect RHFM score ($p<0.05$).

Conclusion: Caregivers of colorectal cancer patients seem to have greater caregiving burden in the postoperative period. For this reason, it is important to provide patients self-care training and encouragement to facilitate their self-care. It will also be beneficial to support caregivers with scheduled education in topics such as stoma care and through support group initiatives.

Keywords: Colorectal cancer, care burden, caregiver, stoma, nursing

ÖZ

Amaç: Kolorektal kanserli hastalara bakım verenlerin bakım yükünün incelenmesidir.

Yöntem: Prospektif, kesitsel ve tanımlayıcı araştırmadır. Örneklemi 1 Ocak-30 Haziran 2015 tarihleri arasında kolorektal kanser nedeniyle ameliyat olan ve Dokuz Eylül Üniversitesi Hastanesi Genel Cerrahi polikliniğine kontrole gelen 162 hasta ve bakım vereni oluşturmuştur. Veriler Hasta ve Bakım Verenler Tanıtıcı Özellikler Formu, Bakım Verenin Stres Ölçeği (BVSÖ) ve Aile Bireyinize Yardımcı Olmaya Gösterdiğiniz Tepkiler Ölçeği (ABYOGT) ile toplanmıştır. Verilerin analizinde sayı, yüzde, ortalama, Mann-Whitney U, Kruskall-Wallis testi, Pearson korelasyon analizi kullanılmıştır.

Bulgular: Hastaların yaş ortalaması 58,5±12,7 ve bakım verenlerin yaş ortalaması 51,8±10,8'dir. Hastaların %51,2'si erkek; %38,9'una (n=63) aşağı anterior rezeksiyon uygulanmış, %66,7'sinin stoması vardır. Bakım verenlerin %58'ini kadınlar oluşturmuştur. BVSÖ puan ortalaması 3,61±3,52 bulunmuştur. Bakım verenlerin ABYOGT puan ortalaması ise 50,50±9,78 saptanmıştır. Hastaların yaş ve stoma durumuna göre bakım yükünün arttığı ($p<0,05$); hastanın cinsiyeti ve ameliyat durumunun bakım yükünü etkilemediği belirlenmiştir ($p>0,05$). Bakım verenlerin yaşı, bakım verdiği gün sayısı ve yardım alma durumu bakım yükünü etkilemektedir ($p<0,05$). Ancak bakım verenin cinsiyeti, medeni durumu ve eğitim durumu bakım yükünü etkilememektedir ($p>0,05$). Hastanın stoma durumu ve bakım verenin cinsiyeti, bakım verdiği süre ve yakınlık durumu ABYOGT düzeyini etkilediği bulunmuştur ($p<0,05$).

Sonuç: Kolorektal kanserli hastaların bakım vericilerinin ameliyat sonrasında bakım yükünün fazla olduğu görülmektedir. Bu nedenle hastaların öz bakımlarını yapabilmeleri için teşvik edilmesi ve öz bakım eğitimi önemlidir. Ayrıca bakım verenlerin de özellikle stoma bakımı gibi konularda planlı eğitimlerle ve destek grup girişimleri gibi yöntemlerle desteklenmesi yararlı olacaktır.

Anahtar Kelimeler: Kolorektal kanser, bakım yükü, bakım veren, stoma, hemşirelik

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Introduction

Colorectal cancer is the fourth most common type of cancer diagnosed worldwide and the second greatest cause of cancer-related deaths. According to 2018 data from the GLOBOCAN database (Estimated global cancer incidence, mortality, and prevalence), a project of the International Agency for Research on Cancer, colorectal cancer ranks third worldwide among the most common cancers overall, third among males and second among females (http://globocan.iarc.fr).[1] According to Turkish cancer statistics from the Republic of Turkey Ministry of Health published in 2017, colorectal cancer is the third most common cancer for both males and females (www.kanser.gov.tr).[2]

With decreases in colorectal cancer incidence and mortality, hospital stays have become shorter and home care has gained importance. A cancer diagnosis affects not only the patient, but also their caregivers and family members.[3,4] The patient being diagnosed with cancer and their family members assuming a caregiving role is a simultaneous process. The primary caregiver is the key person who supports the patient and generally provides the most care. Having a family member with cancer impacts the daily tasks and routines of the household and puts people in new situations to which they must adapt. Cancer is an ongoing, life-threatening disease that prevents the patient from returning to their professional and social lives, and also affects the entire family. These factors increase the responsibilities of the caregiver and change their role in the family.[5]

The magnitude of the care burden perceived by the caregiver is dependent on traits of both the patient and the caregiver. Factors that influence caregiver burden include the severity of symptoms suffered by the patient, the caregiver's age, their relationship to the patient, and their own health.[6] Colorectal cancer operations are major, complex surgeries, and some patients require temporary or permanent stomas. Postoperatively, these patients may experience stomal and peristomal complications (peristomal irritation, parastomal herniation), negative body image, and sexual dysfunction. Patients without stomas may also face problems such as anastomotic leak, surgical site infection, changes in dietary and bowel habits, and sexual dysfunction.[7,8,9] All of these problems intensify the patient's need for physical and psychosocial care, placing an even larger burden on the caregiver. Caregivers fulfill various duties, including providing patients physical, social, and emotional support, arranging their outpatient visits, providing transportation to the hospital, helping perform daily activities in the home, managing their comorbidities and tracking medication, acquiring ostomy care products, and performing or assisting with stoma maintenance.[10] Family members who assume the role of primary caregiver struggle due to the negative impact on their daily activities and the various physical, emotional, psychological, social, economic, and professional problems they experience. As these problems increase, the caregivers' perceived care burden also increases and quality of life is reduced.[4,11,12]

Nurses have a vital role in preparing patients and caregivers for home care during pre-discharge education. The nurse educates the patients and their relatives about how life will be at home after hospital discharge and how they can cope with any problems they face. Determining the burden of care in caregivers of colorectal cancer patients who have undergone surgery should provide guidance in identifying caregivers' needs, meeting these needs early, and planning appropriate nursing initiatives to reduce this burden. Reducing the burden on caregivers is an important step in meeting the optimal care requirements of cancer patients and maintaining effective long-term care, thereby increasing quality of life for both the patient and caregiver. There have been no studies in Turkey related to the burden on caregivers of patients with colorectal cancer after surgery. The aim of this study was to investigate perceived caregiver burden among caregivers of patients operated for colorectal cancer.

Materials and Methods

Research Design

This study was conducted as a prospective, cross-sectional, and descriptive study.

Research Setting

Data were collected in the general surgery outpatient clinic of Dokuz Eylül University Hospital.

Study Universe/Sample

The universe of the study comprised all patients who underwent colorectal cancer surgery and visited the outpatient clinic between January 1 and June 30, 2015, and their caregivers. Criteria for inclusion in the study sample were that the patient was over 18 years old, had a primary diagnosis of colorectal cancer, and was undergoing their first surgery for colorectal cancer. Inclusion criteria pertaining to the caregiver were: being over 18 years of age, being able to speak and understand Turkish, having provided home care for at least 1 month after surgery, and being the spouse or a first-degree relative (child or parent) of the patient.

Data Collection Tools

Data collection tools included patient and caregiver information forms, the Your Reactions to Helping Your Family Member scale, and the Caregiver Strain Index (CSI).

Patient Information Form

The form includes socio-demographic and clinical characteristics such as the patient's age, gender, and marital status, type of surgery, and length of hospital stay (days).

Caregiver Information Form

This form includes socio-demographic characteristics such as the caregiver's age and gender, relationship to the patient, number of children, duration of caregiving, and any caregiving assistance received from others.

Caregiver Strain Index

This tool was developed by Robinson in 1983 to measure the care burden of caregivers, which is assessed using 13 items. There is at least one item in each of five domains: employment, financial, physical, social, and time. Each of the 13 items describes a stressor. The items are answered as yes (1) or no (0). Giving affirmative answers to 7 or more items in the index indicates high stress levels. The total score is calculated by summing the answers (0 or 1) for the 13 items. The Cronbach's alpha value of the scale was found to be 0.86.[13] Validity and reliability studies of the Turkish version of the CSI were conducted by Uğur[14] in 2006, and the Cronbach's alpha value was found to be 0.77. In our study, we determined a Cronbach's alpha of 0.87 for the CSI.

Your Reactions to Helping Your Family Member

This scale is included in the Family Care Inventory developed by Archbold and Stewart (1983). "RHFM" consists of 15 items with subdimensions. The scale was developed to identify caregivers' responses to caring for patients and was restructured in 1993 and 2000. The items in the scale are scored using a 5-point Likert scale as 0: not at all, 1: a little, 2: moderately, 3: a lot, and 4: a great deal. The total score of the RHFM ranges from a minimum of 0 to a maximum of 60. Higher total score corresponds to a larger reaction.[15] Uğur[14] conducted the validity and reliability study of the Turkish version of the scale in 2006 and determined a Cronbach's alpha of 0.88. In the present study, the scale's Cronbach's alpha value was 0.95.

Data Analysis

Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 22.0 software. Socio-demographic characteristics were expressed in numbers and percentages. Pearson's correlation analysis was used to evaluate relationships between caregiver and patient age, length of hospital stay, number of children, number of people supporting the caregiver, and mean CSI and RHFM total scores. Differences between mean CSI and RHFM total scores based on caregivers' socio-demographic characteristics such as gender, marital status, social insurance, employment status, and cohabitation with the patient were analyzed using Kruskal-Wallis test and Mann-Whitney U test. $P<0.05$ was considered statistically significant.

Results

Socio-demographic data of the caregivers are presented in Table 1. The mean duration of caregiving was 36.9±16.39 (min-max: 30-120) days, 78.4% (n=127) of caregivers had no dependents other than the patient, and 80.2% (n=130) received no caregiving assistance.

Mean CSI score of the caregivers was 3.61±3.52 and mean RHFM score was 50.50±9.78. Caregivers reported low stress levels and large reactions to caregiving.

Comparison of caregiving burden according to patient characteristics (Table 2) showed a statistically significant differences in mean CSI score based on presence of stoma (U=1894.0) and in mean RHFM score based on presence of stoma (U=1946) ($p<0.001$).

Analysis of perceived care burden in relation to caregiver characteristics (Table 3) revealed statistically significant differences in mean CSI scores according to relationship to patient (U=11.83), education level (U=14.52), income level (KW=11.69), and caregiving assistance (U=1587.0). Other socio-demographic characteristics of the caregivers (gender, employment, etc.) were not associated with significant differences in their mean CSI scores. There was a statistically significant difference in mean RHFM scores based on gender (U=2518.5) and relationship to patient (KW=14.27).

Caregiving duration was moderately correlated with CSI score ($r=0.392$, $p=0.000$) and weakly correlated with RHFM score ($r=0.242$, $p=0.002$). There were very weak correlations between the other patient/caregiver characteristics and CSI and RHFM scores. A moderate positive correlation was observed between caregivers' CSI and RHFM scores ($r=0.281$, $p=0.000$) (Table 4).

Discussion

In this analysis of the caregiver burden in caregivers of patients who underwent surgery for colorectal cancer, the mean CSI score was 3.61±3.52. This finding indicates low caregiver burden. In a study by Karaaslan[16], caregivers (n=150) of inpatients in the hematology/oncology and gynecologic oncology wards reported a mean caregiver burden of 5.77±2.97, whereas caregivers (n=200) of cancer inpatients and outpatients had a mean caregiver burden of 7.2±3.3 in a study by Yıldız et al.[12] The lower care burden observed in our study may be related to the caregivers being the patients' spouses, being female, being unemployed, and having no other caregiving obligations. In Turkish culture, women are expected to take care of their spouses as a requirement of the family structure and marriage. Lower caregiver strain may be due to the fact that women as spouses perceive caregiving as the responsibility of a wife rather than as a burden.

It has been reported in the literature that caregiver gender does not affect caregiver burden.[5,17,18,19] No differences in magnitude of caregiver burden were observed based on the gender, marital status, employment status, or income of the caregivers. In a study by Orak and Sezgin[18] analyzing care burden of caregivers (n=273) of inpatients in a radiation oncology ward, they determined that marital status of the caregiver was not associated with care burden. In contrast, Karaaslan[16] and Kabataş Yıldız and Ekinci[19] reported that married caregivers with children perceived greater caregiver burden. Being married with children might have increased their caregiver burden because these individuals have the additional responsibilities of housework and child care besides caring for the patient. In our study, low socio-

Table 1. Socio-demographic characteristics of patients and caregivers (n=162)

Patients			**Caregivers**		
Socio-demographic characteristics	**Mean ± SD**	**min-max**		**Mean ± SD**	**min-max**
Age (years)	**58.5±12.7**	**18.0-93.0**	**Age (years)**	**51.8±10.8**	**25.0-75.0**
	n	**%**		**n**	**%**
Gender			**Gender**		
Female	79	48.8	Female	94	58.0
Male	83	51.2	Male	68	42.0
Marital status			**Marital status**		
Single	19	11.7	Single	10	6.2
Married	143	88.3	Married	152	93.8
Chronic disease			**Chronic disease**		
(-)	90	55.6	(-)	136	84.0
(+)*	72	44.4	(+)*	26	16.0
Medication			**Medication**		
(-)	94	58.0	(-)	136	84.0
(+)**	68	42.0	(+)**	26	26.0
Stoma			**Employment status**		
(+)	108	66.7	Employed	30	18.5
(-)	54	33.3	Not employed	132	81.5
Surgery			**Occupation**		
Right/left hemicolectomy	48	29.7	Homemaker	77	47.5
Low anterior resection	63	38.9	Retired	50	30.9
Abdominoperineal resection	42	25.9	Independent/self-employed	26	13.0
Other***	9	5.6	Other****	9	9.5
			Relationship		
			Parent	9	5.5
			Child	40	24.7
			Spouse	113	69.8
			Number of children		
			1-2	114	70.4
			3-4	35	23.4
			0	10	6.2
Total	162	100.0		162	100.0

*Diabetes mellitus, hypertension, hyperthyroidism, asthma, dementia, chronic obstructive lung disease, etc.

**Antihypertensive, antidiabetic, antipsychotic, antidementia drugs, anticoagulants, etc.

***Total colectomy, colostomy, ileostomy ****Civil servant, Laborer, Unemployed

Min: Minimum, Max: Maximum, SD: Standard deviation economic and educational levels were associated with heavier caregiver burden. There are similar data in the literature indicating that caregivers with low education have greater care burden.[18,19,20] It may be that low-educated caregivers have limited abilities to cope effectively with problems (limited access to information, low financial status) or plan care more efficiently. Papastavrou et al.[20] also reported that caregivers with low socio-economic level bear heavier caregiver burden and are in poorer health. Creating an intestinal stoma may be necessary in some patients with

Table 2. Comparison of patients' characteristics with mean Caregiver Strain Index and Your Reactions to Helping Your Family Member scale (n=162)

		CSI*			RHFM*		
Socio-demographic characteristics	**n**	**Mean ± SD**	**Test**	**p**	**Mean ± SD**	**Test**	**p**
Gender							
Female	79	1.64±1.81	U=2963.0	0.269	40.12±12.77	U=2764.0	0.125
Male	83	1.92±2.08			36.25±9.80		
Surgery							
Hemicolectomy	48	1.57±1.34	KW=6.41	0.170	38.78±12.42	KW=4.13	0.388
Low anterior resection	63	2.22±2.48			40.06±11.49		
Abdominoperineal Resection	42	1.57±1.71			38.47±11.15		
Other***	9	0.66±0.50			33.22±2.72		
Stoma							
(+)	108	16.9±2.8	U=1894.0	**0.000****	42.37±10.01	U=1946.5	**0.000****
(-)	54	1.38±1.66			35.06±9.01		

*CSI: Caregiver Strain Index, RHFM: Your Reactions to Helping Your Family Member scale, SD: Standard deviation, **Kruskal-Wallis test, Mann-Whitney U test, p<0.05 ***Total colectomy, colostomy, ileostomy

Table 3. Comparison of caregiver characteristics with Mean Caregiver Strain Index and Your Reactions to Helping Your Family Member scale

		CSI*			RHFM*		
Sociodemographic characteristics (n)	**n**	**Mean ± SD**	**Test**	**p**	**Mean ± SD**	**Test**	**p**
Gender							
Female	94	2.04±2.25	U=2764.0	0.125	40.01±11.17	U=2518.5	**0.011****
Male	68	1.44±1.38			37.20±11.09		
Education level	4	4.00±0.81	KW=14.52	**0.002****	41.75±8.65	KW=2.51	0.472
Literate/Primary school	38	2.26±2.23			39.36±11.36		
High school	88	1.73±2.00			38.65±11.35		
University	32	1.09±1.05			38.31±11.19		
Relationship							
Parent	9	1.71±1.97	KW=11.83	**0.008****	42.57±13.86	KW=14.27	**0.003****
Child	40	2.42±2.04			39.00±11.31		
Spouse	113	4.03±1.41			58.62±12.64		
Income level							
Income less than expenses	11	3.18±1.25	KW=11.69	**0.003****	41.45±10.51	KW=3.759	0.153
Income equal to expenses	141	1.70±1.99			38.41±10.98		
Income greater than expenses	10	1.40±1.50			41.90±14.75		
Caregiving assistance							
(+)	32	2.21±1.66	U=1587.0	**0.030****	40.68±12.10	U=1812.5	0.213
(-)	130	1.68±2.01			38.37±10.95		

*CSI: Caregiver Strain Index (CSI), RHFM: Your Reactions to Helping Your Family Member scale, SD: Standard deviation, **Kruskal-Wallis test, Mann-Whitney U test, p<0.05

Table 4. Correlations between patient/caregiver characteristics and Caregiver Strain Index and Your Reactions to Helping Your Family Member scale

Characteristic		CSI* total score	RHFM* total score
Patient age	r	0.146	0.205
	p	0.063	**0.009****
Caregiver age	r	0.163	0.195
	p	**0.034****	**0.013****
Caregiving duration	r	0.392	0.242
	p	**0.000****	**0.002****
Number of caregiver's children	r	0.144	-0.064
	p	0.069	0.418
RHFM	r	0.281	
	p	**0.000****	

*CSI: Caregiver Strain Index, RHFM: Your Reactions to Helping Your Family Member scale

**Pearson correlation analysis, $p<0.05$ or $p<0.01$

colorectal cancer. Caregivers may have to purchase most of the materials used for colostomy/ileostomy maintenance. This can negatively impact them financially. Consequently, caregivers with low socio-economic status may have faced such problems, which may have resulted in their perception of a larger caregiver burden.

In our study, the mean RHFM score of the caregivers was 50.50±9.7. In a study by Yıldız et al.[12], the average RHFM score of caregivers of cancer patients under inpatient or outpatient care in a hematology/oncology ward was 47.8±11.6. The RHFM scores of caregivers of colorectal cancer patients in our study seem to be higher than those reported in other studies. This strong caregiver reaction may be attributed to the presence of stoma, management of comorbidities, and greater care needs after surgery. In our study, the caregivers of stoma patients had higher caregiver burden and reactions to caregiving. Maguire et al. [4] observed that presence of stoma and general health status affected caregiver burden with colorectal patients. Having a stoma requires caregivers to possess additional knowledge and skills. Therefore, stoma patients have greater care needs. A stoma requires the caregiver to procure supplies and allot extra time in addition to their other daily activities for stoma care, which may increase the perceived care burden and reaction level.

There is evidence in the literature that the burden of caregiving increases with caregiver age[21, 22, 23] Garlo[24] reported that caregivers over the age of 60 who care for cancer patients perceived a caregiving burden and needed assistance from others to meet the patients' daily care needs. In our study, caregiver burden and reaction level increased as caregiver age increased. With older caregivers, the burden of caregiving is thought to increase as a result of their own comorbidities, declining physical health and reduced physical power, and greater difficulty in meeting patient needs (activities of daily living, stoma care, etc).

A positive correlation between caregiving duration and caregiver burden has been reported in the literature.[18,23,25] Hsu et al.[26] found that 61% of caregivers of cancer patients had been in their caregiving role for at least one year and spent about 10 hours a week caregiving. Maguire et al.[4] reported that one-third (n=153) of caregivers of colorectal cancer patients spent more than 25 hours a week providing care. In another study, Eşer and Bedük[27] found that 45.3% of caregivers of cancer patients did not receive assistance while caregiving. In the present study, caregiver burden and reaction level increased with the caregiving duration. Caregivers face many difficulties, including concerns about the cancer relapsing, emotional problems such as hopelessness about the future, difficulties with daily chores, stoma care, and symptom management (diarrhea, pain, fatigue, weight loss, and sexual dysfunction), scheduling appointments, keeping other relatives informed about the patient, reduced or complete lack of income, and disrupted social life. Burdened by these difficulties, caregivers might become sensitive, irritable, or physically and emotionally exhausted.[28,29] It is believed that with prolonged caregiving, the caregivers are exposed to these stressors for longer periods of time, and more pronounced physical (fatigue, cardiovascular diseases, sleeping disorders), emotional, social, and financial problems emerge in the long run, leading to an increased caregiving burden and stronger reaction.

A weak but statistically significant positive correlation was observed between the caregivers' perceived burden and their reaction level. As caregiver burden increases, caregivers show greater reactions to helping their family members. Caregivers' reactions to the patient and to caregiving itself intensify in parallel to the increase in caregiver burden. These stronger reactions might lead to conflict between the caregiver and the patient and negatively affect their quality of life. Therefore, it is important to provide care-related and psychological support to caregivers in order to reduce their reactions to caregiving.

Conclusion

This study investigated caregiver burden and reactions to helping family members among caregivers of colorectal cancer patients. We found that caregiver burden was low, while reactions to caring for a family member were strong. Based on these results, we believe nurses should educate both patients and caregivers, provide motivation and encouragement, and provide stoma care training and support so that patients undergoing colorectal cancer surgery can care for themselves more effectively and the caregiving burden can be further reduced. In order to reduce caregivers' reactions to caregiving, areas of difficulty should be identified, information should be given as needed, and psychological support should be provided during postoperative patient follow-up. The effectiveness of initiatives (e.g., support groups) aimed at reducing the care burden of caregivers of colorectal cancer patients should be evaluated in randomized controlled studies. Caregivers should receive education/training about caregiving preoperatively, and mean scores for pre-training and post-training care burden should be compared.

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Ethics

Ethic Committee Approval: The study was approved by the Dokuz Eylül University non-Interventional Research (approval number: 2015/02-30), and Dokuz Eylül University Hospital Local Ethics Committee (approval number: 99577373-821).

Informed Consent: Informed consent was taken from the patients and caregivers.

Peer-review: External and internal peer-reviewed.

Authorship Contributions

Consept: G.Ö.K., F.V., Design: G.Ö.K., Data Collection or Processing: G.Ö.K., F.V., Analysis or Interpretation: G.Ö.K., F.V., Literiture Search: G.Ö.K., F.V., Writing: G.Ö.K., F.V.

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