

# The Effect of Education Provided to Family Members Caring for Colorectal Cancer Patients on Caregiving Reactions and Healthy Lifestyle Behaviors: A Prospective Quasi-Experimental Study

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## Research Article

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# Abstract

**Purpose:** To evaluate the effects of the educational package provided to enhance family caregivers' experience of colorectal cancer patients receiving chemotherapy on healthy lifestyle and caregiving reactions.

**Methods:** The study was conducted as a pre-test-post-test, quasi-experimental intervention with a control group. The study population consisted of 100 caregivers who provide primary care to patients with colorectal cancer. The data were collected using the "Socio-Demographic Characteristics Data Collection Form", the "Healthy Lifestyle Behaviors Scale-II", and the "Caregiver Reaction Assessment" forms. The pre-test was applied to the experimental and control groups at the first interview. After the preliminary interview, the experimental group was applied three times to face-to-face individual educational sessions through the education booklet prepared by taking the opinions of 5 academician nurses who are experts in the oncology field. The post-test then was applied to the caregivers in the experimental and control groups.

**Results:** After the education provided to the experimental group, a positive change was observed in the mean scores of all sub-dimensions of Healthy Lifestyle Behaviors Scale-II except for the physical sub-dimension. In the control group, there was a statistically significant negative change in the post-test mean scores in all sub-dimensions of the Caregiver Reaction Assessment Scale. Lack of family support in caregivers negatively affected interpersonal relationships, nutrition, health responsibility, and spiritual growth.

**Conclusion:** In order to reduce the problems in family members, it is important to interact with a multidisciplinary approach not only with the patient but also with the caregivers during the chemotherapy process.

**Clinical Trials Identifier;** NCT04791982, 10.03.2021, retrospectively registered

## Introduction

The increasing number of elderly people in society, current healthcare policies, and medical developments have paved the way for providing advanced care at their homes for individuals with life-threatening diseases such as cancer.

Colorectal cancer (CRC) is a health problem with an increasing incidence [4]. CRC diagnosis and treatment process affects not only patients [13] but also their primary family caregivers and can cause significant changes in daily living standards [22]. The family members can take an active role in decisions regarding treatment options in addition to providing support to the patient during the treatment process [9]. They also provide transportation, nutrition, bathing, clothing, psychological and emotional support [23].

The family member providing care has to deal with the adverse effects of the disease and the anti-cancer treatments. Increasing the importance of caregiving has enabled more attention to issues such as quality of life of caregivers, changes in their daily activities, stress management, and prevention of their health problems [15]. In several studies, it was reported that family members had had serious difficulties in helping with symptom management, and what to do in an emergency [18].

Psychological and physical changes experienced by family members in their daily routines negatively affect their reactions to care[17]. Therefore, in order for the caregiver to provide optimal care, it is essential to reduce their stress and help them cope with their problems[6]. Education for caregivers can create a better quality of life and more psychological and emotional support for them and produces improved results for patients[3, 10, 12].

Considering the effects of cancer caregiver burden, a limited number of studies to date have focused on the outcomes of education provided to family members caring for patients with CRC. Due to the paucity of data on the contribution of the education provided for family members caring for CRC, this study aimed to evaluate the effect of education provided for family members caring for CRC patients on reactions for care and healthy lifestyle behaviors.

## **Material And Methods**

### **Study Design**

This prospective study was performed as a pre-test post-test control group quasi-experimental study in oncology service and outpatient chemotherapy units in two different hospitals. Until the end of the study, the patients were cared for by the same family caregiver, changing caregiver family members or formal caregivers were not included in the study. Family members of patients with stage II and III CRC admitted for chemotherapy for the first time between August 2018 and May 2019 were included in the study (n = 133). All participants provided informed consent, and the participants have given their consent in written form.

In order to determine the sample size, it was determined that at least 40 caregiving family members should be included in the intervention and control groups at  $\alpha = 0.05$  level, 95% confidence, and 80% test power, considering the number of patients with CRC per day (stage II and III). The age and education level of family members were matched to ensure similarity in the control and intervention groups. The distribution of patients belonging to the control and intervention groups is given in Fig. 1.

### **Participants**

Caregivers committed to providing care to their patients diagnosed with Stage II/III CRC and agreed to participate in the study and were suitable to respond to the forms, in terms of cognitive and mental health, were included in the study. Caregivers whose patients had previously received chemotherapy for

CRC or had a colostomy in their patients and who had previously been taken education on the subject were excluded from the study.

Socio-Demographic Features, Healthy Lifestyle Behaviors Scale II (HLBS II), and Caregiver Reaction Assessment (CRA) were utilized for outcome measures. The socio-demographic characteristics form, which was formed as a result of the current literature review, includes 24 questions related to socio-demographic and caregiving function characteristics (degree of relationship to the patient, how long he cared for the patient, when his patient was diagnosed, etc.).

The validity and reliability of the HLBS II were performed by Bahar et al, and the scale was reported to be valid and reliable in evaluating the healthy lifestyle behaviors of Turkish society (0.92). The scale is in the form of "4-point Likert", and the lowest and highest scores that can be obtained from the scale are 52 and 208, respectively[1].

CRA was developed in 1992 by Given et al. The validity and reliability study of the scale in our country was performed by Afşar and reported that it is a reliable and valid scale for the Turkish society ( $\alpha = 0.87$ ) [20]. The scale consists of 24 items and five sub-dimensions. While high scores in the sub-dimensions of interruption of daily life, financial problems, lack of family support, and health problems indicate that caregivers are more distressed, and a high score in the self-esteem sub-dimension indicates that caregivers are in good condition[20].

## **Interventions and Data Collection**

### **Experimental group**

Firstly, the literature was reviewed, and an education booklet was prepared after the opinions of 5 academic nurses, who are experts in the field of oncology, were used. The booklet includes CRC treatment in CRC, symptoms that may develop due to chemotherapy and information on their control, psychosocial support of caregiving family members. Interviews and educational sessions with family members, who agreed to participate in the study, were held in the one-on-one and face-to-face meeting room. These interviews lasted approximately 45 to 60 minutes for each family member. In the interviews, an educational booklet containing information on nutrition, exercise, symptom management, physical aspects of care, and disease-specific care was used to present information to caregivers. All of the educational sessions were performed by a single researcher.

### **First interview and education**

First of all, a pre-test was applied to the family member. Following this, the family member was given general information about CRC and the first education and also an education booklet on the effects of chemotherapy. After the education, the caregivers were asked to keep a diary containing any challenges they encountered at home. The family members were given the phone number of the researcher and the information that they could reach the researcher by phone until the end of the process in order to control

the symptoms related to chemotherapy, and also to evaluate the family members physically, socially, and psychologically.

## **Second interview and education**

All caregivers were reached by phone, and the second interview was planned according to the time they will bring their patients for the second cycle of chemotherapy. The interval between chemotherapy treatments of the patients was 14–21 days. The second interview was performed with each caregiver in person and the meeting room. Individualized special education was given to family members by asking them about the challenges experienced while providing home care and by reading the diaries they kept. The content of the education was prepared for the side effects of chemotherapy, problem-solving, what to do in emergencies, and psycho-social situations.

## **Third interview and education**

All caregivers were reached by phone, and the third interview was planned according to the time they will bring their patients for the second cycle of chemotherapy. Similarly, the third interview was also performed with each caregiver in person, and the individualized special education was given to family members by asking them about the difficulties they had the most while providing home care and by reading the diaries they kept. Immediately after the third education, a post-test was applied to the caregivers in the experimental and control groups.

Telephone counseling was given to caregivers who had problems or wanted them between meetings. These are emergencies, chemotherapy follow-up with the port catheter, and side effects of chemotherapy.

## **Control group**

A pre-test was applied to family members caring for CRC patients who met the inclusion criteria and accepted the interview. The date that family members bring their patients for the third cycle of treatment was learned from the nurses working at chemotherapy units, and a post-test was applied. Each family member was given an education and education booklet after the post-test.

## **Statistical analysis**

IBM SPSS® Statistics v25 was used for statistical analysis. The normal distribution of the continuous variables was tested using the Kolmogorov–Smirnov and Shapiro Wilk tests. Student t-test and Mann Whitney U test were used for continuous. Wilcoxon test was used for two dependent variables. Chi-square or Fisher exact tests were used for categorical variable comparisons. Correlation analysis between the sub-dimensions of both scales was calculated using the Spearman correlation coefficient. The healthy lifestyle behaviors and caregiver response evaluation scores for the patients and the caregivers of the experimental group were compared with those of the control group at the beginning and the end of the study. A p-value of less than 0.05 in the 95% confidence interval was considered to indicate statistical significance.

## Results

The demographic characteristics of the caregivers constituting the intervention and control groups are shown in Table 1. Fifty caregivers were enrolled in both groups. The mean age of the caregivers in the control group was  $39.34 \pm 1.34$  (18–69), and the mean age of the caregivers in the experimental group was  $38.87 \pm 1.45$  (18–69). The experimental and control groups had similar characteristics in terms of socio-demographic variables.

Table 1  
Socio-Demographic Characteristics of Caregivers

<b>Socio-Demographic Characteristics</b>	<b>Control (n:50) n (%)</b>	<b>Experiment (n:50) n (%)</b>	<b>P value*</b>
<b>Age</b>	10(20)	10(10)	0,828
18–30	10 (20)	8 (16)	
31–43	20 (40)	22(44)	
44–56	10 (20)	10(20)	
57–69			
<b>Gender</b>	32 (64)	36 (72)	0,394
Female	18 (36)	14 (28)	
Male			
<b>Education Level</b>	13 (26)	14 (28) 6 ( 12)	0,725
Primary School	6 (12)	11 (20)	
Middle School	10 (20)	19 (38)	
High School	21 (42)		
University			
<b>Martial Status</b>	9 (18)	15 (30)	0,217
Single	41 (82)	35 (70)	
Married			
* Students t test and Chi-square test			

The mean age of the patients in the control group was  $61.4 \pm 1.64$  (31–80), and the mean age of the patients in the experimental group was  $62.4 \pm 1.44$  (41–81). 17 (34%) of the patients in the control group had stage II, and 33 (66%) had stage III disease. 27 (54%) of the patients in the experimental group had

stage II, 23 (46%) had stage III disease. It was observed that the patients included in the study had a lower education level in the control group ( $p = 0.004$ ) and had more advanced diseases. ( $p = 0.045$ ).

In all sub-dimensions of the HLBS II scale, it was observed that the experimental group's post-test mean scores were higher than the control group. Except for the physical activity sub-dimension ( $p = 0.689$ ), there was a statistically significant difference between the post-test mean scores between the experimental and control groups in the sub-dimensions of the HLBS II scale (Table 2.). It was observed that the post-test and pre-test mean scores were similar in all sub-dimensions of the CRA scale in the experimental group. However, there was a statistically significant negative change in all sub-dimensions of the post-test mean scores of the control group compared to the pre-test (Table 3.).

Table 2  
Experimental and control groups HLBS II sub-dimensions mean of the scores

Sub-dimensions (n = 100)		Pre-test	Post-test	P value*
		Mean ± SD	Mean ± SD	
Interpersonal relationships	Experimental	2,98 ± 0,48	3,09 ± 0,42	<b>0,001*</b>
	Control	2,76 ± 0,46	2,78 ± 0,47	0,439
	<b>P value**</b>	0,134	<b>&lt; 0,001*</b>	
Nutrition	Experimental	2,52 ± 0,43	2,66 ± 0,36	<b>&lt; 0,001*</b>
	Kontrol	2,35 ± 0,45	2,32 ± 0,43	0,695
	<b>P value**</b>	0,216	<b>&lt; 0,001*</b>	
Health responsibility	Experimental	2,79 ± 0,61	3,01 ± 0,47	<b>&lt; 0,001*</b>
	Control	2,48 ± 0,47	2,53 ± 0,45	0,074
	<b>P value**</b>	0,074	<b>&lt; 0,001*</b>	
Physical activity	Experimental	2,03 ± 0,60	2,05 ± 0,61	0,098
	Control	1,72 ± 0,64	1,83 ± 0,38	0,158
	<b>P value**</b>	0,112	0,689	
Stress management	Experimental	2,58 ± 0,56	2,65 ± 0,54	<b>0,035*</b>
	Control	2,31 ± 0,52	2,34 ± 0,45	0,425
	<b>P value**</b>	0,117	<b>0,021*</b>	
Spiritual growth	Experimental	3,07 ± 0,49	3,13 ± 0,46	<b>0,018*</b>
	Control	2,73 ± 0,58	2,64 ± 0,55	0,054
	<b>P value**</b>	0,055	<b>0,002*</b>	
*Wilcoxon test, SD; **Mann Whitney U test, SD; Standart deviation, HLBS; Healthy Lifestyle Behaviors Scale				

Table 3  
Experimental and control groups CRA sub-dimensions mean of the scores

Sub-dimensions (n = 100)		Pre-test	Post-test	P value*
		Mean ± SD	Mean ± SD	
Self-esteem	Experimental	3,73 ± 0,48	3,62 ± 0,63	0,277
	Control	3,50 ± 0,54	2,63 ± 0,24	<b>&lt;0,001*</b>
	<b>P value**</b>	0,34	<b>&lt; 0,001*</b>	
Lack of family support	Experimental	2,14 ± 0,65	2,16 ± 0,66	0,714
	Control	2,67 ± 0,82	3,72 ± 0,41	<b>&lt;0,001*</b>
	<b>P value**</b>	0,096	<b>&lt; 0,001*</b>	
Financial problems	Experimental	2,59 ± 0,91	2,70 ± 0,89	0,247
	Control	3,12 ± 0,98	3,87 ± 0,59	<b>0,007*</b>
	<b>P value**</b>	0,084	<b>0,007*</b>	
Interruption of daily life	Experimental	2,70 ± 0,72	2,71 ± 0,69	0,674
	Control	3,30 ± 0,74	3,75 ± 0,40	<b>0,004*</b>
	<b>P value**</b>	0,054	<b>0,002*</b>	
Health problems	Experimental	2,31 ± 0,67	2,28 ± 0,64	0,656
	Control	2,87 ± 0,84	3,88 ± 0,36	<b>0,001*</b>
	<b>P value**</b>	0,06	<b>&lt; 0,001*</b>	

\*Wilcoxon test, \*\*Mann Whitney U test, SD; Standart deviation, CRA; Caregiver reaction assessment

It was observed that there was a negative correlation between interpersonal relationships and nutrition sub-dimension of the experimental group HLBS II scale and the lack of family support sub-dimension of CRA scala ( $r=-0.465$ ,  $p = 0.001$ ,  $r=-300$   $p = 0.034$ ). Furthermore, it was observed that there was a positive correlation between the health responsibility and spiritual growth sub-dimension of the HLBS II scale and the self-esteem sub-dimension of the CRA scale, and a negative correlation between the health responsibility and spiritual growth sub-dimension and the lack of family support sub-dimension ( $r=-0.514$   $p < 0,001$ ,  $r=-384$   $p = 0.006$ ). In addition, a moderate negative correlation was observed between the spiritual growth sub-dimension of HLBS II scala and the health problems sub-dimension of CRA scala ( $r =-0.322$ ,  $p = 0.022$ ) (Table 4.). In the control group, there was no correlation between the two-scale scores, between the HLBS II scala sub-dimensions, and the CRA scala sub-dimensions.

Table 4

HLBS II sub-dimensions	CRA sub-dimensions					
		Self-esteem	Lack of family support	Financial problems	Interruption of daily life	Health problems
Interpersonal relationships	r	0,257	-0,465*	-0,171	-0,089	-0,193
	p	0,71	0,001	0,236	0,538	0,178
Nutrition	r	0,122	-0,300*	-0,006	0,018	-0,047
	p	0,400	0,034	0,965	,903	0,746
Health responsibility	r	0,332*	-0,514*	-0,164	-0,162	-0,117
	p	0,019	<0,001	0,256	0,261	0,417
Physical activity	r	-0,032	-0,063	-0,202	-0,057	-0,163
	p	0,828	0,664	0,160	0,694	0,259
Stress management	r	0,117	-0,245	-0,276	-0,192	-0,106
	p	0,418	0,087	0,052	0,183	0,462
Spiritual growth	r	0,284*	-0,384*	-0,200	-0,216	-0,322*
	p	0,046	0,006	0,163	0,132	0,022

\*r; Spearman correlation coefficient, HLBS II; healthy lifestyle behaviors II CRA; caregiving reactions assessment

## Discussion

The increase in outpatient treatments for cancer patients increases the burden of the caregiver in coping with the symptoms related to the disease and treatments. Caregivers play a very important role in symptom management of patients and disease recovery[23]. Changes in caregivers' quality of life and reactions to care directly affect patient care during treatment [18]. With professional face-to-face education, reducing negative effects on caregivers can provide psychosocial support to caregivers and improve patient outcomes [24]. Thus, there should be more focus on making the care experience better quality and accurate via education and the positive outcomes associated with it [25]. To our knowledge, no other study specifically addressed the effects of education provided to family members caring for this patient group on caregiving reactions and healthy lifestyle behaviors.

In our study, the mean HLBS II score was higher in the educated group than the non-educated group, and healthy lifestyle behaviors were significantly better. There was no significant change in the experimental group in terms of only physical activity after education. The likely reason for this in both groups, caregivers spent more than 9 hours a day with the patient, and they did not have time to devote to physical activity. Also, during the follow-up period, there was no other person to care for those being cared for. Beesley et al. found that caregivers, 54% were unable to do physical activity due to their care responsibilities, and 71% were overweight [2]. Gijerset et al. also observed that after an education program for caregivers, their health and social relations improved, but there was no change in their physical activity status [7]. In addition, the traditional lack of physical activity of Turkish society can also be considered as another factor [5].

Previous studies have shown that symptom-focused education provided to caregivers increases care-related skills and reduces negative mood [3, 11, 12]. Hendrix et al. prepared a training program to reduce symptoms and caregiver stress and found that the caregivers who applied this program had higher self-efficacy in symptom management and lower anxiety and depressive symptoms [11]. Harding et al. used a module containing symptom training, social support, and aromatherapy for family members for six weeks and found that the physical, psychological, and social health levels of family members increased after this module [10]. In the study by Belgacem et al it was found that caregivers educated on nutritional support, nursing care, social support, and symptom management had a better quality of life scores and reduced care burden [3]. Furthermore, Leow et al. (2015), in a psychoeducation study, reported that the educated group had higher levels of social support, more interest with the patient, better self-care and quality of life, and lower levels of negative response to care compared to the standard care group [16]. These data are in line with our study and show that education is important for caregivers. Adverse effects associated with colorectal cancer and its treatment, such as weight loss, nausea, diarrhea, pain, dyspnea, insomnia, and fatigue may cause particularly higher caregiver burden in this patient group [19]. This situation reveals the undeniable importance of education for the family member caring for the CRC patient.

In our study, there was no increase in all sub-dimension scores of the HLBS II scale in the control group, and it was lower than the scores of the experimental group. This difference between the groups is consistent with the literature and shows the effect of education and telephone counseling. Studies in which no education, counseling, or similar nursing interventions were carried out have shown that caregivers who try to cope with diseases or symptoms after cancer diagnosis experience poor nutrition, deterioration in personal-social relationships, stress, and burnout related to care [7, 18, 21]. Therefore, understanding the negative effects of cancer experience on caregivers and providing professional support for them is important for the health of both patients and family members.

After the education, while the mean scores of the CRA scale sub-dimension of the experimental group were similar to the pre-education, there was a negative change in the control group. Although this result suggests that education does not make a difference, interestingly, it was determined that the mean scores of the control group increased significantly, although there was no change in the mean scores in the

experimental group. This finding suggests that the experimental group improved their general health and coping skills compared to the control group, in other words, the reaction to the care of the family members who are educated may not become more negative.

The experimental group CRA scale had the highest mean score self-esteem sub-dimension. This may be because, with the effect of education, caregivers are happy to care for and help their loved ones. Hee and Soon showed that caregivers who provided education had better scores on self-esteem and lack of family support sub-dimensions, and also they emphasized that nursing intervention is necessary to increase caregivers' psychological welfare and self-esteem [14]. On the other hand, Grov et al. found a significant difference in the mean scores of only the lack of family support sub-dimension in the caregivers educated, compared to the pre-education level. In addition, they performed the scale again to the same caregivers after four months but reported no statistically significant change in scores [8]. Although the mean scores of the intervention group in the other sub-dimensions were lower, the reason for the increase in the mean scores of the control group CRA scale may be due to the negative reactions of the family members who could not receive support, parallel to the increase in the number of chemotherapy cures.

In the experimental group, the CRA scale subgroup of lack of family support and the HLBS scale interpersonal relationships, nutrition, health responsibility, and spiritual growth sub-dimensions were negatively correlated. The fact that only one person is responsible for the care of the patient, the limitation of daily activities, and the inability to find physical and psychological strength to perform health-protective behaviors are important factors in this. The increasing lack of family support among caregivers negatively affects many healthy lifestyle behaviors. Therefore, focusing on eliminating the lack of family support during education will have serious positive results for caregivers. Previous studies revealed that caregivers who lack family support are affected by their care responsibilities, family and social relations have decreased, and they cannot have health checks [8, 20]. Yu et al. reported a positive correlation between lack of family support and health problems [26], and also they reported a negative correlation between lack of family support and personal success. Similarly, the fact that Avşar (2008) stated that the lack of family support and the interruption of daily life are related, supports our current results [20]. In addition, it was observed that the increase in the self-esteem of the caregivers educated positively affected the health responsibility and spiritual growth, and also the reduction in health problems positively affected the spiritual growth. At this point, reducing the lack of family support with education as well as increasing self-esteem and reducing health problems are the most important components that will positively affect healthy lifestyle behaviors.

Our study had potential limitations. First, family members with CRC were interviewed three times. However, as the chemotherapy process was prolonged, the risk of patients not being able to complete the treatment and the patients coming from outside the province to prefer other hospitals could have caused interruption of the interviews. Therefore, no further interviews were conducted with family members. Second, the population included in the study is small. On the other hand, in order to provide education standardization, the study was performed with a single educationalist and the control and experimental

groups in two different hospitals. It was thought that the increase in the patient population might disrupt standardization and affect the accuracy of the data.

## **Conclusion**

It is important to interact with caregivers during the chemotherapy process to reduce problems in family members. Oncology nurses are in a key position in establishing relationships with family members. Nurses should evaluate the behavior of family members and be able to make behavioral change interventions for families. Especially for cancer caregivers, it is essential to support family members in maintaining healthy lifestyle behaviors such as a balanced diet, taking care of themselves, physical activity, and regular sleep. Therefore, with the education provided to family members caring for CRC patients, negative reactions of family members to care can be reduced, and healthy lifestyle behaviors can have a positive effect.

## **Declarations**

### **Funding:**

The authors have no relevant financial or non-financial interests to disclose.

### **Conflict of interest:**

The authors have no conflicts of interest to declare that are relevant to the content of this article.

### **Availability of data and material:**

The data that support the findings of this study are available from the corresponding author, upon reasonable request.

### **Code availability:**

Not applicable

### **Author contributions:**

NBA has made substantive contributions to the published study, has made substantial contributions to conception and design, and has contributed to data collection, data analysis and drafting the manuscript. TB has been involved in drafting the manuscript and revising it critically for important content. The

authors have read and approved the final manuscript. FCS, has contributed to data collection, data interpretation and revising the manuscript.

## Ethics approval:

We confirm that all patients consented for participation based on the concept of written informed consent. All procedures performed were accordance with the 1964 Helsinki declaration and its later amendments and the study was approved by two hospital institutional ethical board. (Research Ethics Committee of number one Hospital, date: 14.05.2018, decision number: 33478 and Research Ethics Committee of number two Hospital date: 25.06.2018 decision number: 799)

## Consent to participate:

Informed consent was obtained from all individual participants included in the study.

## Consent for publication:

Not applicable

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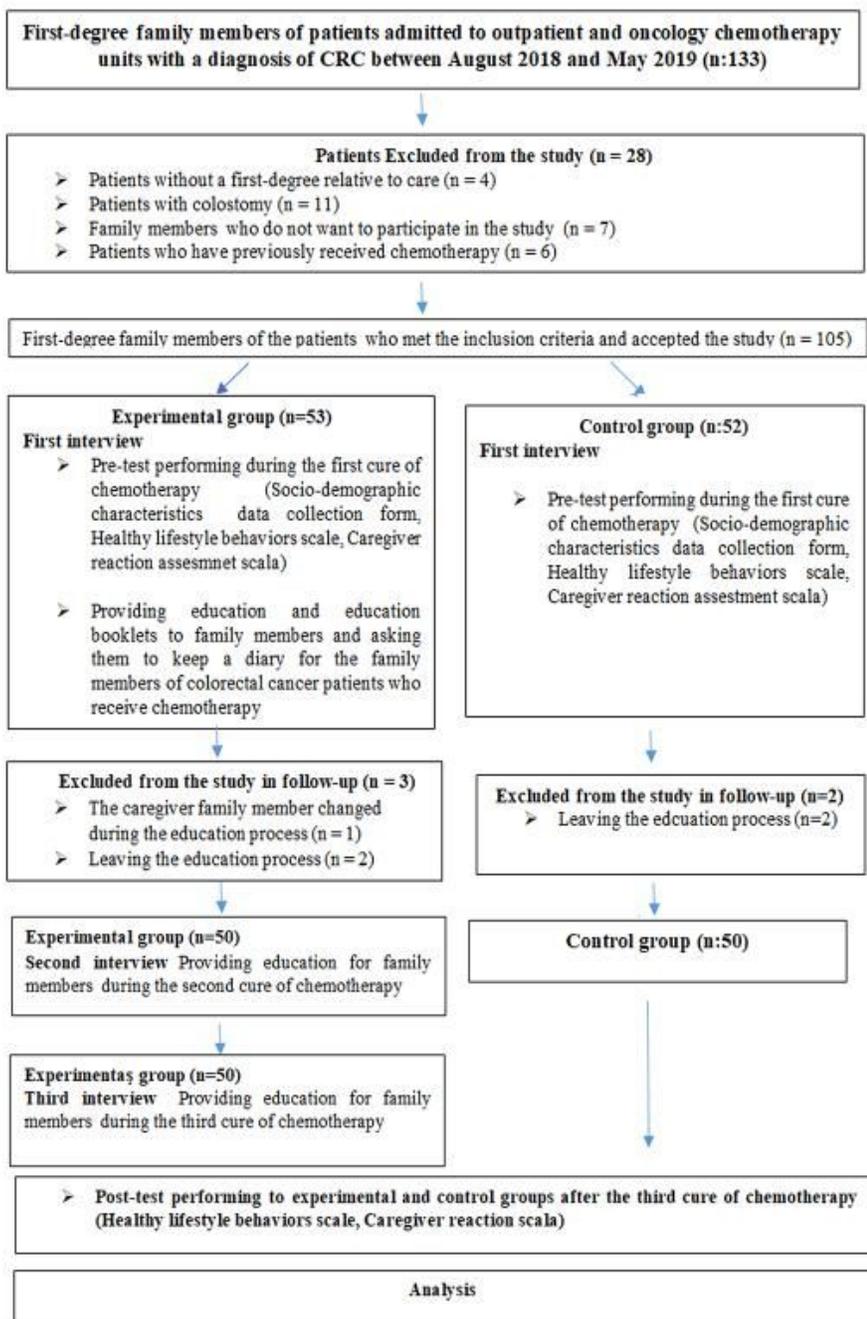
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## Figures



**Figure 1**

Flow chart illustrating the patient selection process (CRC; Colorectal cancer)