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Effect of instructional guidelines on perceived social support level and caregivers' burden of patients having colorectal cancer

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***Abstract*---Background**: Colorectal cancer is a major health risk globally and ranks among the top causes of morbidity and mortality among cancer patients. The adverse impact experienced by caregivers, such as cancer caring burden, reduced free time, and insufficient rest time, could bring both physical and psychological burdens to cancer caregivers. Therefore, the study aimed to evaluate the effect of instructional guidelines on perceived social support level and caregivers' burden of patients having colorectal cancer. **Design**: To carry out this study a quasi-experimental design (pre and post-test one group) was used. **Setting**: This study was conducted at oncology

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outpatient clinics at the oncology institution Sohag City. **Subject**: A convenient sample of 200 (100 colorectal cancer patients and 100 of their caregivers) were enrolled in the current study. **Data collection tools: Tool I:** Participants' demographic and disease-related characteristics assessment sheet, **Tool II:** Caregiver's knowledge about colorectal cancer, Tool **III:** Caregivers' reported practices**, Tool IV:** Zarit Caregiver Burden Interview (ZBI), and **Tool V:** Multidimensional Scale of Perceived Social Support. **Results**: The current study showed that, following instructional guidelines implementation, knowledge, practices, caregiver burdens, and perceived social support ' mean scores were improved with statistically significantly differences. Additionally, the results indicated that total and subscale scores of caregiver burden were negatively correlated with perceived social support. **Conclusion**: Instructional guidelines have a significant effect on improving knowledge and practices among caregivers of patients having colorectal cancer. Similarly, statistically significant reduction of caregiver burdens associated with caring for patients having colorectal cancer with improving in their perceived social support level. **Recommendations**: Caregiver adaptation to caregiving processes should be continuously evaluated, and caregivers should be informed about the possible load and consequences of providing care to protect them from experiencing negative physiological or psychological effects.

***Keywords*---**Burden, Caregivers, Instructional guidelines, Patients having colorectal cancer, perceived social support.

Introduction

Colorectal cancer is the second leading cause of cancer-related deaths worldwide. In 2020, the World Health Organization reported 1.9 million new colorectal cancer cases and 930,000 deaths. The highest incidence rates are observed in Europe, Australia, and New Zealand, whereas Eastern Europe has the highest fatality rates. By 2040, colorectal cancer cases are projected to increase by 63% to 3.2 million annually, with fatalities rising by 73% to 1.6 million per year. This global trend is also evident. According to the Ministry of Health data, colorectal cancer is the third most common malignancy in both sexes (**Sung et al., 2021**). Patients with colorectal cancer frequently have an ostomy following surgery, which causes significant physical and mental distress and increases the nursing burden on caregivers. Nevertheless, the poor quality of life experienced by colorectal cancer patients continues to be a significant challenge for those caring for patients with other types of cancer (**Maguire et al., 2018**).

Caregivers are individuals who give unpaid care to friends, relatives, or life partners who are ill, whether they are patients or disabled. According to **Adib-Hajbaghery** & **Ahmadi (2019),** the burden of core refers to the detrimental effects that caring for individuals with disabilities has on a family caregiver's activities (objective burden) or feelings (subjective burden) pertaining to emotional, physical, social, and financial well- being. Giving care has a significant impact on public health, which impacts millions of people's quality of life. Family caregivers provide social or medical support to other family members. Help with one or more everyday life activities, such as dressing and bathing, paying bills, shopping, and providing transportation, can be a part of caregiving. Support on an emotional level and assistance in managing a chronic illness or disability may also be part of it. As the recipient's needs grow, the number of caregiving duties may also change, putting the caregiver under more stress (**Weis et al., 2021**).

Caregiver burden refers to the various forms of stress and hardship that caregivers experience as a result of providing long-term care for a loved one. The negative effects on caregivers, like the responsibility of caring for someone with cancer, less free time, and not getting enough sleep, can cause physical and mental strain. Indeed, the caregiver load is frequently larger for family members of individuals with colorectal cancer (**Ong et al., 2018**). Family caregivers of patients with colorectal cancer frequently experience a variety of burdens, including role conflict, emotional burden, and time-dependent burden, as well as physical symptoms like fatigue and sleep disturbances and psychological issues like anxiety, depression, and guilt, according to some recent studies (**Mohamed et al., 2021**).

The American gerontologist, Zarit first defined the burden of care as “the discomfort experienced by the principal caregiver of a family member, including the caregiver’s health, psychological and emotional well-being, finances, and social life”. Caregiver burden is defined as “emotional, social and financial stress on patients” **(Yaşar & Terzioğlu, 2022).** or “multidimensional biopsychosocial reaction due to imbalances demanded by official care sources in caregivers' time, social roles, physical and emotional well-being, economic resources, and many other roles they fulfill (**Zuo et al., 2020**)." Psychosocial stress emphasized in the definition of caregiver burden shows the possible relationship with the concept of quality of life, which includes both physical and psychosocial components. The studies reported that the quality of life of caregivers was negatively affected during the caregiving of cancer patients **(Rasul & Amen et al., 2022).**

Additionally, colorectal cancer's high recurrence rate, lengthy treatment regimens, and expensive treatment costs place a significant financial strain on the families of patients. The average yearly growth in colorectal cancer treatment costs in China, for instance, is between 6.9% and 9.2%, and patients' personal medical expenses within a year of diagnosis make up roughly 60% of their family's total income (Wang et al., 2020). A family's entire life is affected by the diagnosis and treatment of cancer. Family crises, diminished intimacy, and disputes among family members can result from chronic physiological, psychological, and social stress. An overburdened caregiver is more likely to experience family maladjustment, and numerous studies have demonstrated that the strain placed on family caregivers has a detrimental impact on family resilience (**Zhang et al., 2022).**

After surgery, patients with colorectal cancer need help from their caretakers because they may have trouble voiding after anal preservation surgery or after a colostomy. A variety of physical and psychological changes also occur in them. This means that about 30% of caregivers will feel exhausted, and that their level of exhaustion will rise over the course of a year. Within six months following the patient's diagnosis, almost 25% of caregivers for patients with colorectal cancer exhibit moderate to severe depression, according to Kim et al (Tran et al., 2020). Furthermore, there is a negative social impact on those who care for patients with colorectal cancer. Numerous studies have demonstrated that in the initial days after a patient with colorectal cancer is discharged from the hospital, caregivers may restrict social interactions out of fear that the patient may not be able to care for themselves. This has a significant impact on the caregivers' daily lives and jobs (**Gray et al., 2020).**

The cost of therapy may fall on caregivers, and work loss or delay may result in an increased financial strain. Caretakers of patients with colorectal cancer currently bear a moderate burden, according to numerous researches. **Shaffer et al., (2019**), the burden of caring for patients with colorectal cancer is influenced by two primary aspects. First, caregivers are impacted by patient-related issues. The findings of the study indicate that while caregivers of patients with difficulties faced a greater care burden, those who were female, younger, and more educated had a lower psychological burden (**Kim et al., 2014**). Second, the care burden is influenced by the caregivers' psychological status and self-efficacy; older, female, employed, and less educated caregivers bear a greater burden, as do caregivers with psychological barriers and low self-efficacy (**Wadhwa et al., 2019).**

Social support has been defined as resources provided by other persons. Social support is one of the fac- tors affecting the caregiving burden of the individuals who help with patient care. It has been reported in previous studies that if the level of perceived social support of caregivers who assist in a patient's care at home is high, the caregiver burden is low (**Yang et al., 2019**).

There is a massive need for more studies assessing the level of knowledge, awareness, and relevant practices toward the prevention of colorectal cancer. Improving knowledge and awareness of the risk factors plays a vital role in lowering the burden of this disease. Moreover, nationally designed programs to increase knowledge, awareness, and correct practices are to date, absent, or insufficient dietary information included the frequency and quantity of consumed foods related to colorectal cancer prevention and initiation, such as fruits, vegetables, dietary fibers, onion, dietary fats, red meats, processed meats, dairy products, and French fries (**Almoshantaf et al., 2022).**

Nurses are essential in helping caregivers join support groups. A support group can offer problem-solving techniques for challenging circumstances, as well as encouragement and validation, because others in support groups are aware of what you might be going through and be an excellent setting for forming deep bonds. Look for social support and try to maintain relationships with loved ones who can provide nonjudgmental emotional support. Schedule a weekly connection activity, even if it's only going for a walk with a friend (**Wong et al., 2021).**

Significance of the Study

In Egypt, the incidence of cancer was 166.6 per 100,000 for both sexes, 175.9 per 100,000 for men, and 157.0 per 100,000 for women. One of the most prevalent malignant tumors of the digestive tract is colorectal cancer. Global Cancer Statistics 20201 states that colorectal cancer has the third-highest incidence and second-highest fatality rate worldwide. Nonetheless, surgery, radiation, chemotherapy, and targeted therapy are all increasing the survival rate of individuals with colorectal cancer (**Sung et al., 2021**).

In Egypt, 58% of informal caregivers for cancer patients were women, 88% looked after a relative, 39% lived with the patient, 50% reported high emotional stress from providing care, and 73% participated in hospital care discussions; however, 43% reported needing assistance in managing both emotional and physical stress. At the end of life, 40% of respondents sought assistance (**Onyeneho & Hesanmi, 2021**). Caregivers, especially spousal caregivers, face a significant caregiving, emotional, and financial burden during the treatment process (**Chen et al., 2022).**

As primary caregivers, spouses are responsible for meeting the daily living, illness care, and emotional support needs of the patient, while also fulfilling additional family and social responsibilities. However, neglecting physical and psychological well-being due to the heavy caregiving load, making them more susceptible to health problems such as fatigue, anxiety, and depression than patients , thus creating caregiver burden that results in physical, psychological, emotional, and financial losses associated with providing care (**Saji et al., 2021**). Hence, the study was done to evaluate the effect of instructional guidelines on perceived social support level and caregivers' burden of patients having colorectal cancer.

Aim of the study:

The study aimed to evaluate the effect of instructional guidelines on perceived social support level and caregivers' burden of patients having colorectal cancer

Hypothesis:

H1: Caregivers' knowledge and reported practices for patients having colorectal cancer will be improved post- instructional guidelines implementation than pre- implementation.
H2: Caregivers' burden level caring for patients having colorectal cancer will be decreased post- instructional guidelines implementation than pre- implementation.
H3: Caregivers' perceived social support level caring for patients having colorectal cancer will be improved post- instructional guidelines implementation than pre- implementation.

Subjects and Methods

Research Design:

A quasi-experimental design (pre and post-test one group) was used.

Setting:

This study was conducted at oncology outpatient clinics at the oncology institution Sohag City.

Subjects:
A convenient sample of 200 (100 colorectal cancer patients and 100 of their caregivers) were enrolled within six months.

Data collection tools:

Tool I: Participants’ demographic and disease-related characteristics assessment sheet: it included data such as (gender, age, education level, and residence), Time since diagnosis (Months), Cancer stage, and received treatment.

Tool II: Caregiver's knowledge about colorectal cancer: It was created by the researchers based on a literature review (Saji et al., 2021; Sung et al., 2021; Chen et al., 2022) and written in simple Arabic language. It was created to evaluate the caregiver's knowledge of colorectal cancer disease and consists of 20 items: (2) meaning, (3) symptoms, (3) causes, (3) high risk, (2) methods to colorectal cancer detection, (2) types of cancer, (2) prevention, and (3) information sources.

Scoring system:
Correct answers received a score of (2), while correct and incomplete answers received a score of (0). The sum of the item scores was divided by the number of items and the total knowledge scores were deemed satisfactory if the score were > or equals 60% and considered unsatisfactory if the score were < 60%.

Tool III: Caregivers' reported practices:
It was developed by the researchers based on a literature review (**Yang et al., 2019; Almoshantaf et al., 2022)** and written in simple Arabic language. Using 10 questions that were divided into 4 categories of colorectal cancer patient follow-up, exercise of patients with colorectal cancer, administering medication, screening to patients, with colonoscopy followed by the Faecal Occult Blood Test.

Scoring system of caregivers' reported practices:
There are two response levels for each step: completed and unfinished. For each of these, the scores were 1, 0. When the score was greater than or equal to 60 %, the total reported procedures were deemed adequate; when it was less than 60 %, they were deemed inadequate.

Tool IV: Zarit Caregiver Burden Interview (ZBI):
The Zarit Caregiver Burden Interview (ZBI) was created in 1980 by **Zarit and Zarit (1990**). Inci and Erdem conducted a validity and reliability study of its Turkish version in 2008, and the Cronbach Alpha Value is between 0.87 and 0.99. It is a structured questionnaire (interviewer-administered) that functions as a rating scale. It measures the impact of caregiving on an individual's life and consists of 22 statements. It is a Likert type scale that rates on a scale of 0 to 4 points, with 0 representing "never," "rarely," "sometimes," "frequently," and "always." The scale's lowest score is 0 and the highest is 88. The items are primarily focused on the social and emotional domains, and a score of 0–20 indicates "no care burden.", 21- 40 “low care burden”, 41-60 “medium care burden “ and 61-88 means “heavy care burden” (**Inci & Erdem, 2008**).

Tool V: Multidimensional Scale of Perceived Social Support: (MSPSS): Using data from three different sources, this scale type subjectively assesses the characteristics of social support. Eker et al. conducted a study in 2001 to examine the validity and reliability of the version. The scale's dependability ratings are 0.89 for the entire scale and 0.85 for each of its three sub-dimensions, which measure social support perceived "from family," "from friends," and "from significant someone." MSPSS consists of twelve components. A 7-interval scale is used to grade each item. As the score for each item increased, so did the perceived level of social support; the total scale had a minimum score of 12 and a maximum score of 84, while the sub-dimensions had a minimum score of 4 and a maximum score of 28. The practitioner could assign at least 1 point to a statement that was not agreed with and a maximum of 7 points to a statement that was agreed (**Eker et al., 2001**).

Scoring system:
The item scores were varied from 0 to 84 which displayed as follows: low Perceived Social Support was 0-> 28, moderate Perceived Social Support was 28-<56, and high Perceived Social Support was 56-84.

Validity and reliability of tools: Five medical-surgical nursing, education, and community health nursing experts evaluated the instruments for comprehensiveness, applicability, clarity, relevance, and comprehension to conduct content validity. No changes were made when needed. Using the Cronbach's alpha test, reliability was assessed; it was 0.931 for knowledge, 0.933 for practices, and 0.879 for burden of care.

Pilot Study:
Twenty caregivers, or 10 % of the sample, participated in a pilot study to make sure the questions were clear, the instruments were applicable, and the time required to complete them was adequate. No ambiguous statements or questions were present, and no changes were made. Pilot study was included in the study.

Ethical Considerations:
This study was approved by the Sohag University Faculty of Nursing's Ethical Scientific Research Committee. After being informed of the study's goals and advantages, caregivers of patients having colorectal cancer verbally consented to take part. In accordance with ethics, values, cultures, and beliefs, participants were granted the freedom to leave the study at any moment, and confidentiality and anonymity were upheld.

Field work:
The purpose of the study was explained, and each caregivers of patients having colorectal cancer was interviewed after giving their informed consent to take part. The researchers established the educational instructions in a clear, Arabic language after studying relevant literature and making revisions and modifications based on expert feedback. A pilot study was conducted to see whether the questions were straightforward and unambiguous. The data was gathered for three hours every day, two days a week, from the beginning of July to the end of December 2021.

Construction of the guidelines:

Four phases make up the current study: assessment, planning, implementation, and evaluation.

Assessment stage: pre-assessment tools were completed. This stage used to collect information from caregivers of patients having colorectal cancer.

Planning stage:

As a consequence of the pre- instructional guidelines assessment, literature study, researcher experience, and the perspectives of nursing and medical experts, the instructional guidelines were developed.

The general objective of the instructional guidelines was to reduce the caregivers' burden of care and enhance their reported practices, knowledge, and improve their perceived social support level.

Guidelines contents: The instructional guidelines' content was developed to meet the needs of caregivers and to match their level of interest and comprehension. These included:

Knowledge about colorectal cancer disease

- Meaning
- Symptoms
- The causes
- High risk

- **Methods to colorectal cancer detection**
- **Types of cancer**
- **Prevention**

Reported practices among caregivers of patients having colorectal cancer

- Colorectal cancer patient follow-up
- Exercise of patients with colorectal cancer
- Administering medication
- Screening to patients, with colonoscopy followed by the Faecal Occult Blood Test

Implementation stage:

- Three theoretical and two practical sessions, each lasting thirty minutes, were used to discuss the instructional guidelines with caregivers. The researchers have one-to-one meetings with each caregiver.
- In addition to caregivers completing the study materials, the first session included an explanation of the guidelines and their purpose. In the first session, interviews with patients having colorectal cancer conducted to gather demographic information and related health history.
- In the second session; Meaning, Symptoms, The causes, and High risk was covered.
- In the third session Methods to colorectal cancer detection, Types of cancer, and Prevention was covered.
- In the fourth session colorectal cancer patient follow-up and Exercise of patients with colorectal cancer was covered.

- In the fifth session Administering medication and Screening to patients, with colonoscopy followed by the Faecal Occult Blood Test was covered
- Printed colorful materials and handouts with the instructional guidelines were distributed to caregivers.
- A summary of the previous session's topics was given at the start of each one.

Evaluation stage:

The effect of instructional guidelines on perceived social support level and caregivers' burden of patients having colorectal cancer was re-assessed using the same data collection tools after completion of the guidelines.

Statistical analysis:

The collected data were examined before being entered into a computer and the Statistical Package for Social Science (SPSS) version 20 was used to conduct statistical analysis. The data was displayed in tables using the t-test, Chi-square, number, percentage distribution, mean, and standard deviation. P-value is considered significant if it is equal or less than 0.05 and very significant if P-Value is 0.001.

Results:

Table (1): portrays that 57% of the caregivers in the study their ages were ≥ 30, 54% were female, 51% had a Basic education, and 41% were employed. It showed that; 63 % of the studied patients were male and 60 % their ages were < 30 years old. Regarding Time since diagnosis (Months, it was observed that 56% of the patients in the study had the disease from < 6. Concerning Cancer stage, it was noticed that 39 % were in stage III and 45% of them had Surgery + Chemotherapy + Targeted therapy as received treatment for cancer.

Figure (1): Illustrates that the main source of knowledge among caregivers caring for patients having colorectal cancer was doctors (75%).

Table (2): This table showed that there was improvement in caregivers' total knowledge mean scores from 10.22±1.56 to 17.22±1.34 with a statistically significant difference detected between **caregivers'** knowledge mean scores post-instructional guidelines than pre- instructional guidelines at P value < 0.001

Figure (2): Shows that the total knowledge level of the studied caregivers has improved post instructional guidelines **about** colorectal cancer and also illustrated, that 18% of them had a good level of knowledge of pre- instructional guidelines that improved to 89% post- instructional guidelines.

Table (3): Illustrates that there was a highly statistically significant difference between caregivers' practice caring for patients having colorectal cancer **pre- and post-** instructional guidelines a p-value <0.001. Where there was improvement in **caregivers' total** practice mean scores from 5.11±1.23to 8.05±1.22.

Figure (3): Shows that 20% of the studied caregivers had satisfactory practice pre- instructional guidelines that improved post- instructional guidelines among (87%) of the studied caregivers.

Table (4) and Figure (4): Illustrates that there is a highly statistically significant difference between caregivers' ZBI score means caring for patients having colorectal cancer **pre and post-** instructional guidelines a p-value <0.001. Where there was reduction in **caregivers'** ZBI mean scores where 17% had “no” care burden pre - instructional guidelines which increased to be 30% post-instructional guidelines.

Table (5): Illustrates that there was a highly statistically significant difference between caregivers' Perceived Social Support caring for patients having colorectal cancer pre and post- instructional guidelines a p-value <0.001. Where MSPSS Sub-dimensional score means are; 20.4±8.2 in “perceived social support from significant someone” dimension and improved to be 26.04±8.2, 21.01±7.65 in “perceived social support from families” dimension and improved to be 28.01±7.65, 17.02±8.5 in “perceived social support from friends” dimension and improved to be 24.02±8.5. Also, there was improvement in caregivers' total Perceived Social Support mean scores from 58±20.95 to 78.05±1.22 post-instructional guidelines.

Figure (5): Shows that no one (0) of the studied caregivers had high perceived social support level pre- instructional guidelines that improved post- instructional guidelines among (65%) of the studied caregivers.

Table (6) illustrates a statistically significant correlation between total knowledge, total practices, perceived social support, and total burden of care among caregivers of patients having colorectal cancer, pre and post instructional guidelines.

Table (1): Participants’ demographic and disease-related characteristics (n=200).

Demographic data	**(Caregivers’ Characteristics)**		**(Patients’ Characteristics)**			
	No	**%**		**No**		**%**
Gender			**Gender**			
Male	46	46		Male	63	63
Female	54	54		Female	37	37
Age			**Age**			
<30	43	43		<30	60	60
≥ 30	57	57		≥ 30	40	40
Residence			**Time since diagnosis (Months**	<6	**56**	**56**
Rural	85	85		6~	**28**	**28**
Urban	15	15		≥12	**16**	**16**
Educational level			**Cancer stage**	I	9	9
Illiterate	20	20		II	27	27
Basic education	51	51		**III**	**39**	**39**
Secondary education	21	21		IV	25	25
University education	8	8	**Received treatment**	Surgery + Chemother	45	45

Demographic data	**(Caregivers' Characteristics)**		**(Patients' Characteristics)**			
	No	**%**		**No**		**%**
				apy + Targeted therapy		
Working				Surgery + Chemotherapy	21	21
Not work	46	46		Chemotherapy + Targeted therapy	24	24
Employee	41	41		**Others**	**10**	**10**
Farmer	13	13				

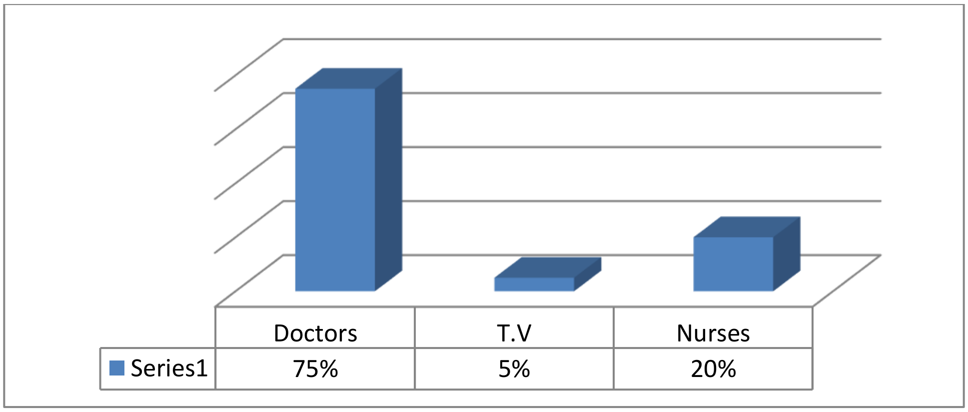
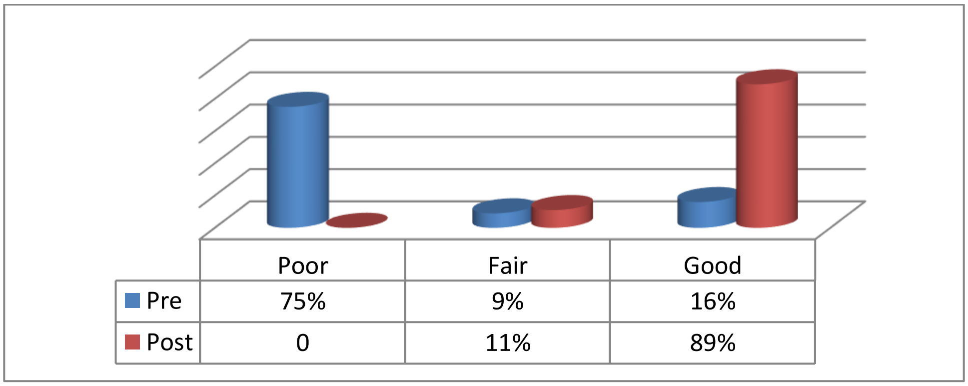


Figure (1): Source of knowledge among caregivers caring for patients having colorectal cancer

Table (2): Total mean scores of caregivers' knowledge having colorectal cancer pre and post- instructional guidelines (n=100)

Caregivers' knowledge	**Pre**	**Post**	**P-value**	**t-test**
Knowledge Mean Score	10.22±1.56	17.22±1.34	<0.001**	67.21

*- independent t-test ** Significant difference at p. value<0.01*



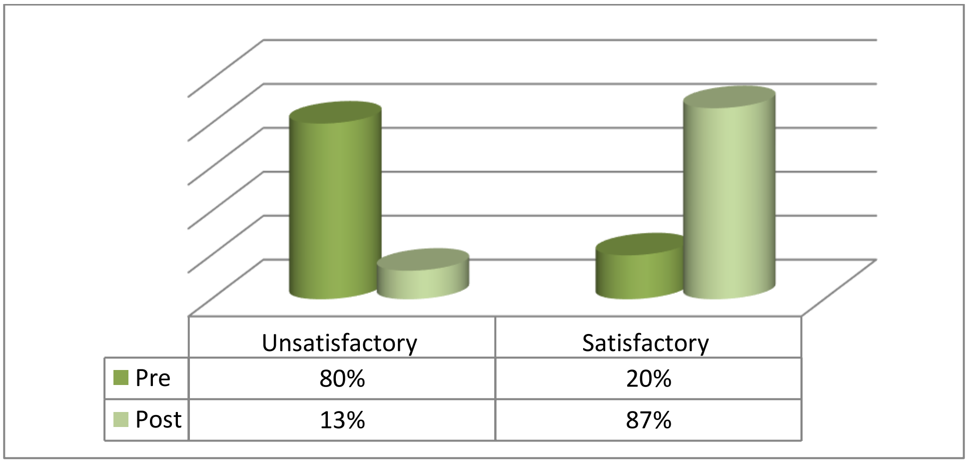
	Poor	Fair	Good
🟦 Pre	75%	9%	16%
🟥 Post	0	11%	89%

Figure (2): Caregivers total knowledge levels caring for patients having colorectal cancer pre and post- instructional guidelines (n=100).

Table (3): Total mean scores of caregivers' practices caring for patients having colorectal cancer **pre and post-** instructional guidelines **(n=100)**

Caregivers' practices	**Pre**	**Post**	**P-value**	**t-test**
Practices Mean Score	5.11±1.23	8.05±1.22	<0.001**	45.32

*- independent t-test ** Significant difference at p. value<0.01*

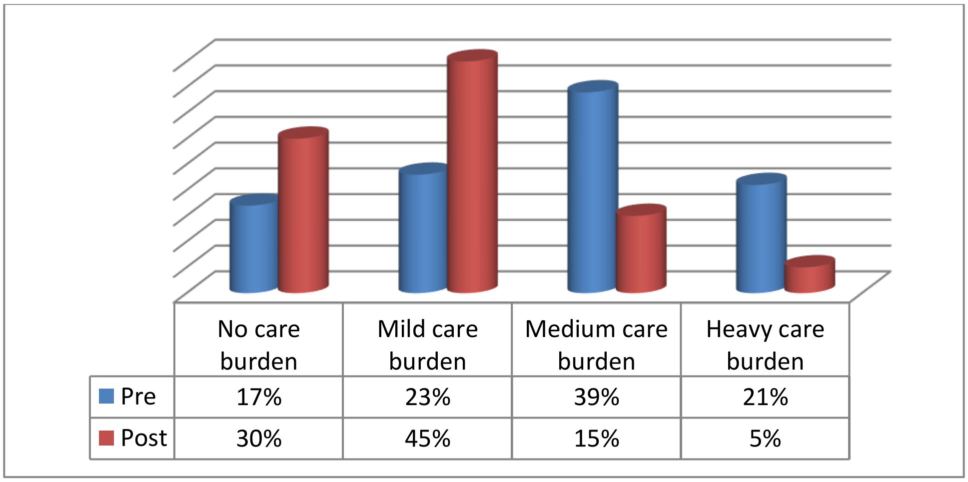


	Unsatisfactory	Satisfactory
🟩 Pre	80%	20%
🟩 Post	13%	87%

Figure (3): Caregivers total practices levels caring for patients having colorectal cancer pre and post- instructional guidelines (n=100).

Table 4. The Mean ZBI Scores of the Caregivers caring for patients having colorectal cancer pre and post- instructional guidelines (n=100).

Care Burden	**Range**	**Pre**		**Post**		**P-value**
		n	**%**	**n**	**%**	
No care burden	0-20	17	17	30	30	<0.001
Mild care burden	21-40	23	23	45	45	
Medium care burden	41-60	39	39	15	15	
Heavy care burden	61-88	21	21	5	5	



	No care burden	Mild care burden	Medium care burden	Heavy care burden
🟦 Pre	17%	23%	39%	21%
🟥 Post	30%	45%	15%	5%

Figure (4): Total burden level among caregivers caring for patients having colorectal cancer pre and post- instructional guidelines (n=100)

Table 5. Total Mean Perceived Social Support Scores of the Caregivers caring for patients having colorectal cancer pre and post- instructional guidelines (n=100).

MSPSS sub-dimensions	**Min-Max**	**Pre**	**Post**	**P-value**	**t-test**
Perceived social support from significant someone	4-28	20.04±8.2	26.04±8.2	<0.001**	76.54
Perceived social support from families	4-28	21.01±7.65	28.01±7.65		
Perceived social support from friends	4-28	17.02±8.5	24.02±8.5		
Total Perceived Social Support Mean Score	12-84	58±20.95	78.05±1.22		

*- independent t-test ** Significant difference at p. value<0.001*

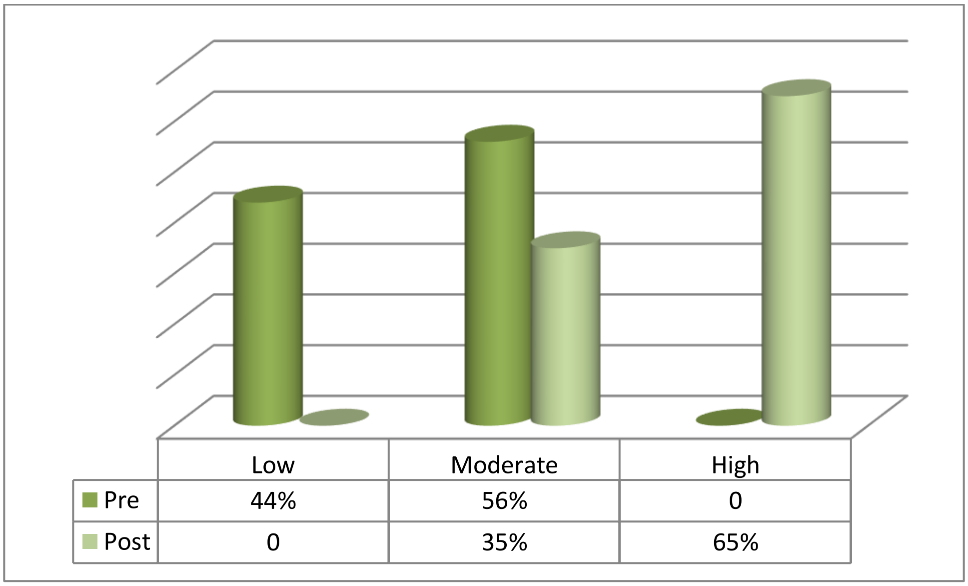


Figure (5): Total Perceived Social Support level among caregivers caring for patients having colorectal cancer pre and post- instructional guidelines (n=100)

Table (6): Correlation matrix between total knowledge, total practices, perceived social support, and total burden of care among caregivers caring for patients having colorectal cancer pre and post- instructional guidelines (n=100)

Items	Pre					Post			
	Total knowledge		Total practices	MSPSS	Total burden of care	Total knowledge	Total practices	MSPSS	Total burden of care
Total knowledge	r	1	.142	.152	-.633	1	.076	1	.513
	p-value		.056	.076	.001**		.257		.001**
Total practices	r	.143	1	1	.317	.076	1	.133	.745
	p-value	.057			.001**	.257		.058	.024*
Total burden	r	-.632	.322	.356	1	.513	.739	.656	1
	p-value	.001**	.001**	.001**		.001**	.024*	.001**	
Perceived social support MSPSS	r	-.632	.322	1	.322	.513	.739	1	.322
	p-value	.001**	.001**		.001**	.001**	.024*		.001**

***Highly significant P<0.001*

Discussion:

Cancer is ranked as the third leading cause of mortality globally, and its patient population is growing. While the application of the most recent technology has contributed to improved prognoses, more work is still required. This causes suffering not only for the patient but also for the caregivers and family members. Cancer patients and their caregivers must receive training on how to manage their symptoms and cope with this illness (**WHO, 2021).**

A family member of a cancer patient has a negative impact on their emotional, social, and financial well-being. Many countries have strong family ties and traditions that are maintained. Family members thus feel happiness as well as sadness. In the inpatient care, this social characteristic is preserved during the therapeutic process. Caregivers at this phase are usually first-degree relatives. They occasionally provide emotional support as well as assistance with the patient's treatment. According to **Gok Metin et al. (2019**), a poor hospital environment can result in a variety of problems, but it also provides emotional fulfillment for the caregiver. Negative reactions to the ways in which providing care impacts the caregiver's social, professional, and personal duties are one way to define caregiver load **(Ogunyemi et al., 2021). So,** the study aimed to evaluate the effect of instructional guidelines on perceived social support level and caregivers' burden of patients having colorectal cancer.

The current study found that more than half of the caregivers were female and were ≥ 30, more two fifths did not have jobs and more than half of them were in basic education. In their various studies, **Ogunyemi et al. (2021), Akpan-Idiok & Anarado (2019), Boostaneh et al. (2021), Gabriel et al. (2019), Jite et al. (2021), and Sun et al. (2022**) demonstrated that women bear the primary responsibility for providing care for patients with cancer. Our study's participants' average age was 40.4 years, which was higher than the 35.9 and 39.71 years that **Akpan-Idiok (2021**) reported. This implies that the majority of healthcare professionals who treat cancer patients are in their fourth or fifth decade of life. Furthermore, the results of **Gabriel et al. (2019**) that most caregivers are between the ages of 41 and 50 are supported our study.

Our findings differed from those of **Yasar & Terzioglu (2022), Ogunyemi et al. (2021**), and others who suggested that parents and relatives were the primary caregivers, respectively. Our study offers fresh perspectives by recognizing sisters as possible primary caregivers in particular cultural or familial contexts, even if parents and other family members are frequently the primary caregivers.

According to the demographic data of the patients in the current study, two fifths of the patients were over thirty years old, and more than three fifths of the patients were male. According to **Ramasubbu et al. (2020**), 40% of their patients shared the same age range.

Concerning Cancer stage, it was noticed that slightly less than three quarters were in stage III and less than half of them had Surgery, Chemotherapy, and Targeted therapy as received treatment for cancer. The findings align with those of **Zou et al. (2020**), who noted that the most common types of interventions were chemotherapy and surgery. Similar to **Rasul & Amen (2022**), radiation, chemotherapy, and surgery were used as treatments. These results are in line with those of **Yesilbalkan et al. (2019**), who found that three-quarters of their patients had cancer that had been there for three years and that most of their patients had taken chemotherapy. On the other hand, almost one-third of patients received radiation treatment; according to **Rezaei et al. (2020**).This could be because chemotherapy is the first line of treatment for cancer after surgery and has been shown to be effective. **Wenhao et al. (2021**), who found that more than half of informal caregivers were unemployed, supported these findings.

According to the current study, three-quarters of caregivers for patients with colorectal cancer said that doctors were their primary source of information. It affirmed that caregivers learn from the appropriate sources.

The current study revealed that there was improvement in **caregivers' total** knowledge mean scores with a statistically significant difference detected between **caregivers'** knowledge mean scores post- instructional guidelines than pre-instructional guidelines. This demonstrated, in the researcher's opinion, the important impact of instructional guidelines. These results are in line with those of **De Lamaza et al. (2020),** who discovered that carers' clinical outcomes were enhanced and their knowledge levels were elevated by structured instruction. Furthermore, these results are in line with those of **Belongacem et al. (2019**), who discovered a significant statistical relationship between the caregivers' overall knowledge before and after the program. This could be due to the influence of instructional guidelines that enhance caregivers' understanding.

According to the current study, caregivers' total level of knowledge, the current study revealed that the total knowledge level of the studied caregivers has improved post instructional guidelines **about** colorectal cancer. The findings are consistent with other studies on cancer patients and cancer patients having surgery by **Beaver et al. (2019**), which show that information support and phone follow-up effectively increase awareness levels regarding the disease. The family caregivers in the study had strong understanding about cancer prior to the educational guidelines intervention, and their knowledge improved following the intervention, according to **El-Amin et al. (2021**). These discrepancies, according to the study, may result from the impact of rules and reinforcement that increase caregivers' understanding.

The current study revealed that there was a highly statistically significant difference between caregivers' practice caring for patients having colorectal cancer **pre and post-** instructional guidelines and there was improvement in **caregivers' total** practice mean scores from 5.11±1.23to 8.05±1.22. From the researcher's point of view, it confirmed the success of instructional guidelines which caused knowledge improvement and associated with practice improvement.

The current study revealed that one fifth of the studied caregivers had satisfactory practice pre- instructional guidelines that improved post- instructional guidelines among the majority of the studied caregivers. According to **Eliana's (2019**) research, about 50% of the study's caregivers received satisfactory practice scores for the treatment of their cancer patients prior to the intervention, and that percentage increased to over 75% following the intervention. According to the researchers, these differences might be the consequence of how well the guidelines improve caregivers' practices and accomplish the objective of the current study. According to the current study, there is a highly statistically significant difference between caregivers' ZBI score means caring for patients having colorectal cancer **pre and post-** instructional guidelines. Where there was reduction in **caregivers' ZBI means** scores post- instructional guidelines. The causes of the previous findings, according to the researchers, could range from psychological, social, and physical health problems to overall health outcomes. The duration and timing of the caregiving role have a significant impact on the caregiver's mental health. These outcomes were consistent with **Oboh & Adaonfo's (2019**). The caregiver burden was much lower for those who shared the care, according to **Shieh et al. (2022**). According to research by **Yigitalp et al. (2017) and Seo & Park (2019)**, having a helper lessens the strain on the caregiver.

In a similar vein, **Yildirim et al. (2013**) found parallel results and established that caregivers' burden levels were low because it is only natural for relatives to care for the needy patients, and caregivers view this as a natural duty and responsibility. Although caregivers face hardships during the caregiving process, they are expected to treat their patients at home, which may indicate that they are unaware of the care burden or that they fully submit to it as a result of learned helplessness; 28.70±16.14 in caregivers of patients receiving three or more chemotherapies; 21.75±9.66 in caregivers of patients receiving fewer than three chemotherapies (**Oksuz et al., 2013**) and similarly 36.65±11.21 in caregivers of patients with cancer (**Turkoglu & Kilic 2012**).

Onyeneho & Hesanmi (2021) found that after the intervention, just 5% of the caregivers in their study had a high total burden of care, compared to 75% before the intervention. One possible explanation for this could be the study's findings, which show that caregivers experience light to heavy loads. Nonetheless, the study did discover that most caregivers felt only a slight amount of stress. Because of their relationship with the care recipient, most people are reluctant to express their ideas, even in the face of the stress. This makes sense.

Shim & Ng, 2019; Sanjeevani et al., 2022; Mirsoleymani et al., 2019 and other studies also revealed a significant level of burden. The high burden of care may be due to both time and financial constraints, as many of the patients in our study experienced financial hardships, which often had a negative impact on the caregivers' physical and mental health.

The present study found a highly statistically significant difference between caregivers' Perceived Social Support caring for patients having colorectal cancer pre and post- instructional guidelines. From the perspective of the researchers, these result reflected the positive effect of instructional guidelines that enhance caregivers' knowledge and practices and improve their perceived social support. Related literature shows that perceived social support has a protective role. In fact, studies on this protective role were also examined in a sample of caregivers of cancer patients and it was concluded that perceived social support has a protective role. One of the reasons why such a protective role could not be achieved within the scope of this study may be related to the participants' normal level of stress (**Demırtepe-Saygılı et al., 2021**).

The present study found no one of the studied caregivers had high perceived social support level pre- instructional guidelines that improved post- instructional guidelines among about two thirds of the studied caregivers. Another situation related to social support is how willing caregivers are for this support or how suitable they are for this support relationship. In a study that included caregivers of cancer patients within the scope of the "The Cancer Family Caregiving Experience" model, it was stated that maintaining friendships, social relationships and social life was difficult for most of the participants. It is stated that at the beginning of the diagnosis period, some caregivers isolate themselves from their environment and avoid discussions about the disease. While some caregivers avoid this social environment themselves, some caregivers report that they were abandoned by others, and this creates a great distress for them (**Stamataki et al., 2019).**

The present study found a statistically significant correlation between total knowledge, total practices, perceived social support, and total burden of care among caregivers of patients having colorectal cancer, pre and post instructional guidelines. The findings were corroborated by **El-Amin et al. (2021**), who investigated the knowledge, attitudes, and practices of caregivers of cancer patients in Sudan. They discovered that the total knowledge, total practices, and total burden scores of the caregivers for older adult cancer patients they evaluated had a strong statistically significant correlation. This could be because the strain placed on caregivers of cancer patients may differ depending on the stage of the disease and other patient-related circumstances.

Parallel findings are also reported by pertinent literature investigations. According to **Chiou et al. (2019),** caregivers who receive social support experience a mild care burden, and care burden tends to decrease as perceived social support rises. **Cooper et al. (2013**) have also observed a strong correlation between caregivers' care burdens and informal social support. According to **Goldstein et al. (2014),** caregivers who have little social support bear a heavier burden of care.

This result can be explained in several ways: The first one has to do with conventional social organization. Family support is a lifelong experience under this structure, and family concepts and collaboration among family members and even relatives are highly valued. However, some reports suggest that traditional family structures may result in over-dependent family relationships that increase emotional load (**Kuscu et al., 2019**). Additionally, social circle attempts to offer support may occasionally be interpreted by the recipient as attempts to control and interfere, which may have a negative impact on the individual and raise stress levels (**Karakoc & Yurtsever, 2018**).

Indeed In his research, **Barber (2013**) found that friends' social support positively affects the motivation of caregivers who assist cancer patients. It is well known that people feel more mentally connected to others in their age group. In that scenario, social support from friends and a particular someone may have an impact on the care burden score, while social support from family may not. Furthermore, according to **DOkmen (2022**), social support may not be sufficient to mitigate the effects of caregiver stress. Consequently, in addition to meeting caregivers' support requirements through their friends, family, spouses, or other special people; it's also essential to support needs of caregivers in a systematic and directly relevant way on an institutional base to minimize the negative effects of caregivers' burden.

Several studies in the literature support this study (**Bradley et al., 2019; Daly et al., 2019; Preksha & Kaur, 2016; Shieh et al., 2022; Yigitalp et al., 2017).** The study found a statistically significant moderate negative correlation between the mean ZCBS and MSPSS scores ($p<0.05$). It also found that the caregiver burden increases as the caregiver's social support decreases, meaning that there is a negative relationship between the two.

Conclusion

Based on the current study findings the current study concluded that instructional guidelines have a significant effect on improving knowledge and practices among caregivers of patients having colorectal cancer. Also, statistically significant reduction of caregiver burdens associated with caring for patients having colorectal cancer with improving in their perceived social support level.

Recommendations:

Based on the findings of this study, therefore recommend the following suggestion:

- The assessment of social support systems in coordination with caregivers may yield effective results in raising caregivers' awareness of this issue. - As an alternative solution, it is considered necessary to offer professional consulting services to caregivers on the issue of social support and encourage them to receive such services.
- Caregivers should be informed about the potential burden and consequences of the care giving process and their adaptation into care processes should be closely monitored throughout this process to prevent them from experiencing negative physiological or psychological effects from heavy care burden.
- In order to provide care in a comprehensive way, it is recommended that caregivers be included as well. As a result, they should be informed about the disease and the hospital environment, appropriate arrangements should be made for meeting their personal care needs, and a variety of social events should be planned.
- Creating handbooks, pamphlets, and brochures to provide up-to-date information about colorectal cancer.
- Creating strategies to improve the relationship between patients and caregivers so that both parties can actively lessen the burden on caregivers and improve the perceived level of social support for colorectal cancer management;
- More evidence-based intervention studies can be developed and put into practice to assist families with colorectal cancer in navigating the cancer crisis.
- To generalize the results, the study should be repeated on other samples and in various settings.

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