

## Effect of Educational Guidelines for Family Caregivers of Elderly Cancer Patients Regarding Burden of Care

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### Abstract

**Background:** Cancer is a serious disease placing the family caregiver at a higher risk of burden which is a significant issue for caregivers who caring for elderly cancer patients. **Aim of the study** was to evaluate the effect of educational guidelines for family caregivers of elderly cancer patients regarding burden of care. **Design:** A quasi-experimental design was used. **Setting:** The study was conducted at Oncology Out-Patient Clinic in Benha teaching Hospital. **Subjects:** Simple random sample were used; it includes 200 patients, and their family caregivers were chosen randomly from the mentioned setting. **Tools of data collection:** Four tools were used. **I-** A structured interviewing questionnaire: Consisted of 2 parts to assess: 1) Demographic characteristics of elderly cancer patients and their caregivers: 2) Medical history of the elderly cancer patients. **Tool II:** The family caregiver's knowledge about cancer disease. **Tool III:** Family caregivers' reported practices. **Tool IV:** Zarit Burden Interview to assess family caregivers' burden of care. **Results:** There were general improvements regarding family caregivers' knowledge and practice regarding cancer with highly significant difference ( $P \leq 0.001$ ), and family caregivers' burden of care decreased to 40.5% post educational guideline. There was highly statistically significant correlation between total knowledge, total practices, and total burden scores of the studied family caregivers. **Conclusion:** The educational guidelines had a significant effect there was a significant decrease in family caregivers' burden of care. There was highly statistically significant correlation between total knowledge, total practices, and total burden scores of the studied family caregivers for elderly patients with cancer. **Recommendations:** Advocate family caregivers about supportive services help in caring elderly people with cancer.

**Keywords:** Educational guidelines, Family caregivers, Burden of care & Elderly cancer patients

### Introduction

Cancer is a malignant, neoplasm, tumor and genetic term for a large group of disease that can affect any part of the body. In the most basic terms cancer refers to cells that grow out of control and invade other tissues. Cells may become cancerous due to the accumulation of defects as BRCA1 and BRCA 2 mutations) and infections can increase the risk of cancer. Environmental factors as air pollution and poor lifestyle choices such as smoking and heavy alcohol use can also damage DNA and lead to cancer (World Health Organization 2021).

Cancer is the second leading cause of death globally, accounting for an estimated 9.6 million deaths. In 2020 an estimated 1,806,590 new cases of cancer will be diagnosed in the world and 606,520 older adult patients will die from the disease prostate, lung, and colorectal cancers account for an estimated 43% of all cancers diagnosed in men by year 2020. While the three most common cancers are breast lung and colorectal, and account for estimated 50% of all new cancer diagnosis in women by year 2020 (National Cancer of Health (NCH), 2020)

Family caregivers are people who provide care to the family members, life partners or friends who's sick, either older adult patient's or disabled, without paid. Burden of care was defined as a negative impact of caring for impaired persons experienced by family caregiver on the activity (objective burden) or feeling (subjective burden) that involves emotional, physical health, social life, and financial status (Annisa, 2016; Adib-Hajbaghery & Ahmadi, 2019).

Caregiving is important for public health that affects the quality of life for millions of individuals. Family caregivers help another family members with social or health needs. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping, and providing transportation. It also may involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the recipient's needs increase, which may result in additional strain on the caregiver (Weis et al., 2021).

Family caregiver burden is a complex response to physical, psychological, emotional, social, and

financial stressors associated with the caregiving experience. This multidimensional process affects the biological, psychological, sociological, ethnic, cultural, and religious aspects of formal caregivers' lives. For caregivers of cancer patients, caregiver burden was heavier for those who were younger, male, single, and with primary school education or below. In this setting, the burdens of family caregiving may include not only physical tasks but also emotional distress, since caregivers tend to neglect their own needs on behalf of the patient (Rezaei et al., 2020).

An obvious signs and symptoms of family caregiving stress and burden of care are often psychological problems; most commonly anxiety, depression, irritability feeling tired and run down, difficulty sleeping, overreacting to minor problems, new or worsening health problems, trouble concentrating feeling, smoking, or eating more (World Health Organization, 2021).

Community health nurse plays a vital role to help family caregivers to join with support group. A support group can provide validation and encouragement, as well as problem-solving strategies for difficult situations. Because persons in support groups understand what may be going through. And be a good place to create meaningful friendships. Seek social support, make an effort to stay, connected with family and friends who can offer nonjudgmental emotional support. Set aside time each week for connecting, even if it's just a walk with a friend (Zauszniewski et al., 2021).

### Significant of the Study

Incidence rates of cancer in Egypt 100,000 were 166,6) both sexes), 175,9 (males), and 157.0 (females). Commonest sites were liver (23.8%), breast (15.4%), and bladder (6.9%). Incidence of informal family caregivers for patients with cancer in Egypt: 58% were women, 88% cared for a relative, 39% lived with the person being cared, 50% reported high emotional stress related to caregiving, 73% were involved in discussion about care during hospitalization; however, 43% reported needs for help managing emotional and physical stress. 40% wanted help making end of life decisions (Onyeneho & Hesanni, 2021).

### Aim of the study:

The study aimed to evaluate the effect of educational guidelines for family caregivers of elderly cancer patients regarding burden of care.

### Research objectives:

1. Assessing family caregivers' knowledge about cancer.

2. Designing, implementing, and evaluating the effect of an educational guidelines on decreasing family caregivers' burden of care.

### Hypothesis:

Family caregivers' knowledge and practices regarding cancer disease in elderly patients will be improved after the implementation of an educational guidelines, also family caregivers' burden of care will be decreased.

## Subjects and Methods

### Research Design:

The study used a quasi-experimental research design.

### Setting:

The present study was carried out at the Oncology Out-Patient Clinic in Benha Teaching Hospital for family caregivers with cancer patients.

### Subjects:

**Type:** Simple random sample.

**Size and technique:** The study was conducted on 20% of the total cancer elderly patients diagnosed in last year 2020 attending at Oncology Out-Patient Clinic in Benha Teaching Hospital. The total number of study sample were 200 patients out of (1000). So, family caregivers were be taken randomly.

### Data Collection Tools:

**Researchers collected data using four different tools:**

**Tool I- A structured interviewing questionnaire,** created by the researchers based on literature review. And written in simple unambiguous Arabic consisted of two parts as the following:

**Part one:** It was designed to gather data about the demographic characteristics of elderly cancer patients (sex, age, level of education, marital status, work, income, and residence.) and their family caregivers' demographic characteristics. It involved questions about sex, age, level of education, marital status, work, income, relativeness, and time of caring.

**Part two:** It was concerned with the medical history of the elderly cancer patients. Which include 28 items; (6) about types of cancer, (4) about duration of disease, (4) about received treatment, (8) about pervious disease, (4) about pervious surgery during last year, (2) about taken medication know.

**Tool II-** It was developed to assess the family caregiver's knowledge about cancer disease, which include 39 items; (5) about meaning, (5) about symptoms, (5) about causes, (4) about high risk, (5) about methods to detect cancer, (5) about types of cancer, (5) about dangers symptoms to get doctor, (5) about source of information.

**Scoring system:** The correct answer was scored (2), while the correct and incomplete answer was scored

(1) and incorrect answer was scored (0). For each question of knowledge, the score of the items was summed- up and the total divided by the number of the items. The total knowledge scores were considered good if the score of the total knowledge >75%, considered average if it equals 60-75%, and considered poor if it less than 60%.

**Tool III:** The study focused on family caregivers' stated practices related daily living assistance of elderly patients with cancer which included 36 items that divided into 6 categories about cancer patient follow up, 6 items about give medication, 4 items about practices regarding pain, 4 items about practice regarding fever, 4 items about practices regarding anorexia, 4 items about nausea, 4 items about practices regarding constipation, 4 items about practices regarding infection.

**Scoring system for family caregivers' practices:**

Each step has 2 levels of answers: Done, and not done. These were respectively scored 1, 0. Total practices were considered satisfactory if the score > or equals 60% and considered unsatisfactory if the score < 60%.

**Tool IV- Zarit Burden Interview (ZBI):** It was adapted from (Grün, et al., 2016), which the researchers translated to assess family caregiver's burden. The ZBI is a questionnaire with 22 items. The family caregiver determines the frequency of various social, economic, and health aspects in relation to the caring experience on a three-point Likert scale 2 if always, 1 if sometimes and 0 if never.

**Scoring system:**

A total score is calculated by summing the score of items, which ranged from 0 – 66 and presented as; no burden 0-20, moderate burden 21-40, and high burden 41-66.

**Validity and reliability of tools:**

Content validity was done by five experts in the field of the study who reviewed the tools for clarity, relevance, comprehensiveness, understanding, and applicability. Minor modifications were done as required. Reliability was measured by using Cronbach, alpha test (reliability for knowledge was 0.941, practices and management was 0.901, and for burden of care was 0.926).

**Pilot Study:**

A pilot study was conducted on 20 family caregivers representing 10% of total sample to ensure the clarity of question, applicability of the tools and the time needed to complete them. There were no unclear questions, or statements and no modification were done. So, pilot subjects were later included in the study.

**Ethical Considerations:**

Approval was obtained orally from family caregivers of elderly cancer patients to participate in the study after explanation the purpose and benefits of the study. Participants were given a right to withdraw from the study at any time, principles of confidentiality and anonymity were maintained with respect of ethics, values, cultures, and beliefs.

**Field work:**

- Official permissions were received from Benha Teaching Hospital administrative director.
- Each family caregiver for elderly cancer patients was interviewed after describing the study's aim and obtaining informed consent to participate in the study.
- Educational guidelines were created by the researchers after reviewing of related literature, then revised and modified according to the expertise feedback, it was written in clear, Arabic language.
- A pilot study was carried out to see if the questions were clear and simple.
- The data was collected in the period from beginning of May to the end of October 2021, two days weekly for three hours/daily.

**Construction of the guidelines:**

The current study was divided into four stages; assessment, development, implementation, and evaluation.

**Guideline's assessment stage:** A pre assessment was done, using the previous interviewing questionnaires. This phase aimed to gather data from family caregivers of elderly cancer patients.

**Guideline's development stage:**

The educational guidelines were created based on the actual results that were obtained from pre-guidelines assessment, literature review, researchers experience and nursing and medical expertise's viewpoints.

**General objective of the educational guidelines** was to improve knowledge and reported practices of family caregivers and decrease burden of care.

**Guidelines contents:** The content of the guidelines was created to satisfy family caregiver's needs and to correspond to their degree of interest and level of understanding. These contents were:

**Knowledge about cancer disease**

- Meaning.
- Signs and symptoms.
- Causes.
- High risk.
- Diagnosis.
- Types of cancer
- Source of information
- Dangerous symptoms to get doctor

**Practices regarding family caregivers' self-care and health**

- Eating well- balanced diet.
- Participation in hobbies and routine activities.
- Techniques for rest and relaxation.
- Create time for self
- Consistent follow up.
- **How to organize family caregiving time to reduce burden of care.**
- **How to share care with supported persons.**
- **How to find community resources (medical, financial, social....etc) that can help.**

**Guideline's implementation stage:**

- The educational guidelines were addressed with family caregivers over the course of seven sessions (3 theoretical and 4 practical), each lasting 30 minutes. The researchers meet with each family caregiver one-on-one.
- The first session featured an introduction to the guidelines and their purpose, as well as family caregivers filling out the research materials. Elderly cancer patients were interviewed in the first session to obtain demographic data and assess medical history.
- The educational guidelines were presented to family caregivers in the form of handouts and printed material. It included diagrams, pictures with colors to attract and guide caregivers.
- Each session began with a summary about what had been discussed in the previous one.

**Guideline's evaluation stage:**

After completing the guidelines, an immediate posttest was conducted using the same data gathering instruments to assess the educational guidelines' effectiveness.

**Administrative and ethical considerations:**

An official approval was obtained and delivered from Dean of Faculty of Nursing, Benha University directed to the Director of Benha Teaching Hospital, then to security manager, and security officer, lately consent of family caregiver of elderly cancer patients. Where the study was conducted concerned the title, objectives, tools, and the study technique will be illustrated to gain their cooperation which is needed to allow the researcher to meet the family caregivers in Oncology Clinic at the Benha Teaching Hospital. The investigator took an oral consent from family caregivers of elderly cancer patients to take part in the research at any point, the participant has the option to withdraw. The confidentiality of the information was ensured.

**Statistical analysis:**

Prior to computerized entry, the obtained data were checked, and statistical analysis was performed using the Statistical Package for Social Science (SPSS) version 20. The mean, standard deviation,

number, percentage distribution, and Chi-square were used to portray the data in tables. P-Value > 0.05 was regarded inconsequential, P-Value 0.05 was considered significant, and P-Value 0.001 was considered highly significant.

## Results

Table (1): Frequency distribution of family caregivers regarding demographic characteristics (n=200).

Socio-demographic characteristics	No.	%
<b>Age</b>		
20<30	30	15.0
30<40	110	55.0
40<50	34	17.0
≥50	26	13.0
<b>Mean ± SD 38.95±5.41</b>		
<b>Gender</b>		
Male	76	38.0
Female	124	62.0
<b>Level of education</b>		
Illiterate	31	15.5
Basic education	64	32.0
Secondary education	71	35.5
University education	34	17.0
<b>Occupation</b>		
Not work	68	34.0
Government employee	52	26.0
Private Job	38	19.0
Farmer	42	21.0
<b>Income</b>		
Enough and saving	9	4.5
Enough	24	12.0
Not enough	167	83.5
<b>Relativeness</b>		
Son	28	14.0
Daughter	111	55.5
Husband\wife	56	28.0
Friends	5	2.5
<b>Living in same place</b>		
Yes	183	91.5
No	17	8.5
<b>Time of caring</b>		
1<2	55	27.5
2<3	114	57.0
≥3	31	15.5

Table (2): Frequency distribution of patients regarding demographic characteristics (n=200).

Demographic characteristics	No	%
<b>Age</b>		
60<75	119	59.5
75<85	76	38.0
≥85	5	2.5
<b>Mean ± SD 63.52±7.41</b>		
<b>Residence</b>		
Rural	157	78.5
Urban	43	21.5
<b>Gender</b>		
Male	141	70.5
Female	59	29.5
<b>Marital status</b>		
Single	18	9.0
Married	70	35.0
Widowed	99	49.5
Divorced	13	6.5
<b>Educational</b>		
Illiterate	47	23.5
Basic education	100	50.0
Secondary education	40	20.0
University education	13	6.5
<b>Working</b>		
Not work	96	48.0
Employee	75	37.5
Farmer	17	8.5
Craft worker	12	6.0
<b>Income</b>		
Enough	22	11.0
Not enough	178	89.0

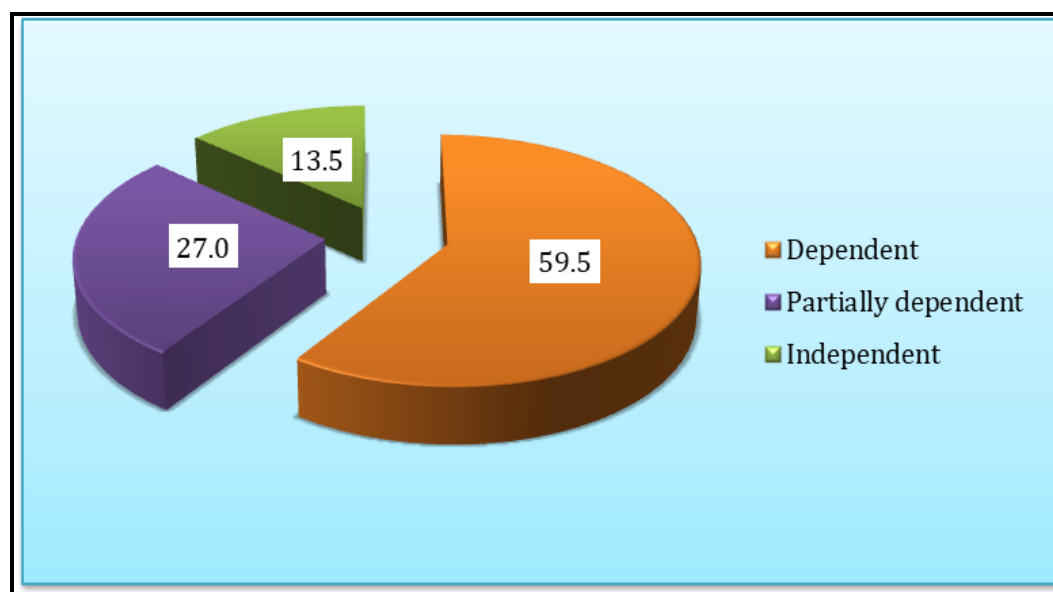


Figure (1): Percentage distribution of patients regarding their dependency level (n=200).

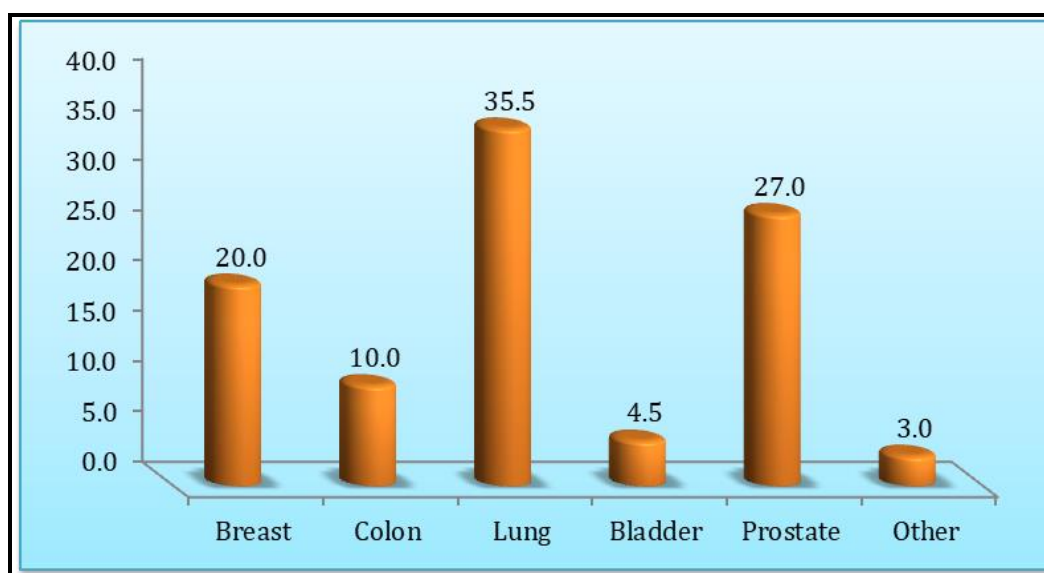


Figure (2): Percentage distribution of patients regarding their type of cancer (n=200).

Table (3): Frequency distribution of patients regarding medical history (n=200).

Medical history	No	%
<b>Duration of cancer disease</b>		
<3years	140	70.0
3<5years	60	30.0
<b>Treatment used for cancer</b>		
Chemotherapy	140	70.0
Radiotherapy	28	14.0
Hormone therapy	18	9.0
Surgery	14	7.0
<b>Co-morbid diseases</b>		
Yes	31	15.5
No	169	84.5
<b>When answer with yes what's the disease (n=169)</b>		
Respiratory system disease	14	8.3
Arterial heart disease	6	3.6
Hypertension	77	45.6
Kidney disease	11	6.5
Diabetes mellitus	80	47.3
Musculoskeletal diseases	12	7.1
<b>Have any operation during the previous years</b>		
Yes	82	41.0
No	118	59.0

*Results not mutually exclusive*



Table (4): Frequency distribution of family caregivers regarding their knowledge about cancer pre and post educational guidelines (n=200).

Knowledge	Pre- educational guidelines						Post- educational guidelines						X2	P-value
	Correct & complete answer		Correct & incomplete answer		Incorrect answer		Correct & complete answer		Correct & incomplete answer		Incorrect answer			
	No	%	No	%	No	%	No	%	No	%	No	%		
Meaning of cancer	16	8.0	94	47.0	90	45.0	113	56.5	67	33.5	20	10.0	122.0	.000**
Symptoms of cancer	7	3.5	100	50.0	93	46.5	69	34.5	92	46.0	39	19.5	73.00	.000**
Cause of cancer	15	7.5	98	49.0	87	43.5	100	50.0	72	36.0	28	14.0	97.07	.000**
High risk group	15	7.5	130	65.0	55	27.5	84	42.0	90	45.0	26	13.0	65.74	.000**
Screening for cancer	18	9.0	132	66.0	50	25.0	103	51.5	79	39.5	18	9.0	88.08	.000**
Types of cancer	23	11.5	115	57.5	62	31.0	86	43.0	80	40.0	34	17.0	50.86	.000**
Dangerous symptoms that require going to the doctors	15	7.5	127	63.5	58	29.0	86	43.0	85	42.5	29	14.5	67.89	.000**

\*\*Highly significant  $P < 0.001$

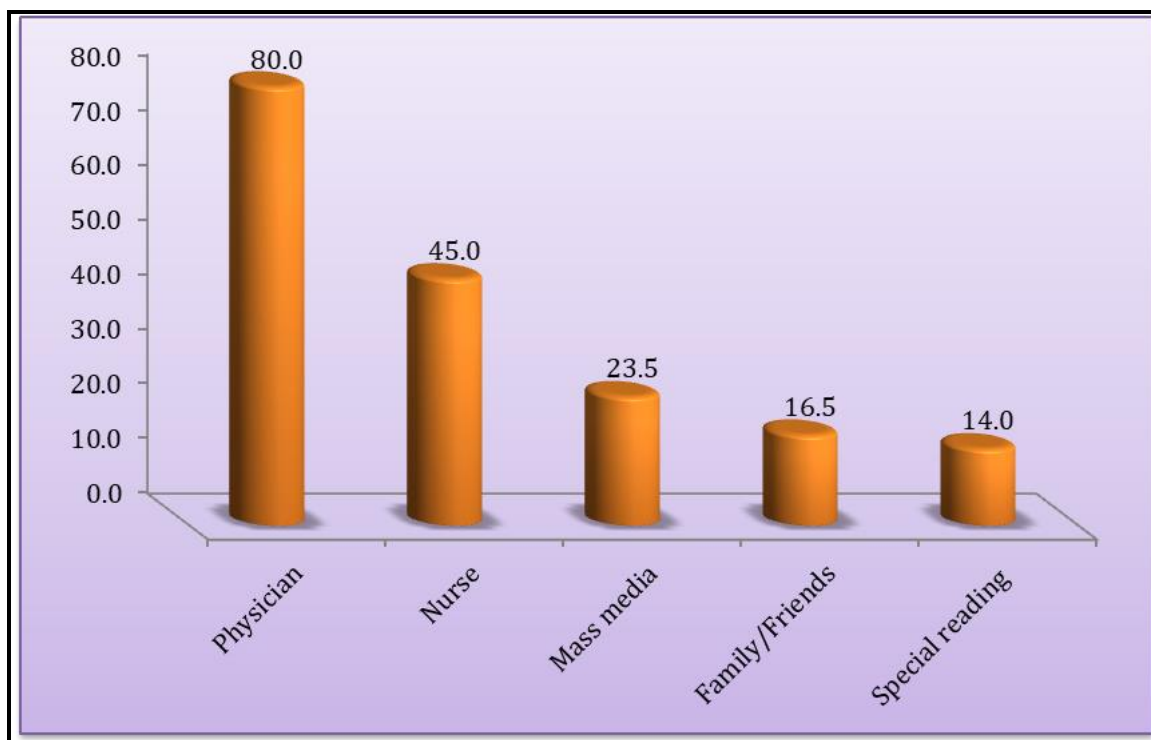


Figure (3): Percentage distribution of family caregivers regarding source of knowledge (n=200).



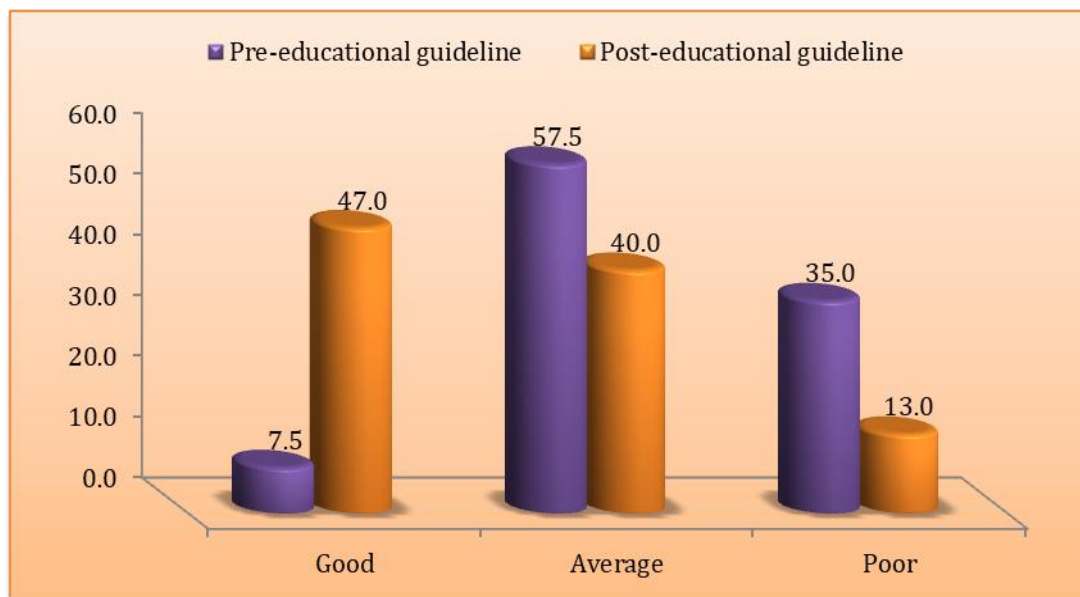


Figure (4): Percentage distribution of family caregivers regarding total knowledge pre and post educational guidelines (n=200).

Table (5): Frequency distribution of family caregivers regarding their total practices and management of symptoms pre and post educational guidelines (n=200).

Items	Pre- educational guidelines				Post- educational guidelines				X <sup>2</sup>	p-value
	Satisfactory		Un satisfactory		Satisfactory		Un satisfactory			
	No	%	No	%	No	%	No	%		
Personal hygiene	80	40.0	120	60.0	163	81.5	37	18.5	72.22	.000**
Nutrition	62	31.0	138	69.0	118	59.0	82	41.0	31.67	.000**
Giving medication	73	36.5	127	63.5	119	59.5	81	40.5	21.19	.000**
Follow-up	88	44.0	112	56.0	119	59.5	81	40.5	9.62	.002*
Management of pain	72	36.0	128	64.0	161	80.5	39	19.5	81.42	.000**
Management of fever	78	39.0	122	61.0	160	80.0	40	20.0	69.75	.000**
Management of anorexia	72	36.0	128	64.0	160	80.0	40	20.0	79.47	.000**
Management of nausea	63	31.5	137	68.5	160	80.0	40	20.0	95.35	.000**
Management of constipation	69	34.5	131	65.5	157	78.5	43	21.5	78.77	.000**
Management of infection	77	38.5	123	61.5	136	68.0	64	32.0	34.95	.000**

\*Significant  $P < 0.005$

\*\*Highly significant  $P < 0.001$

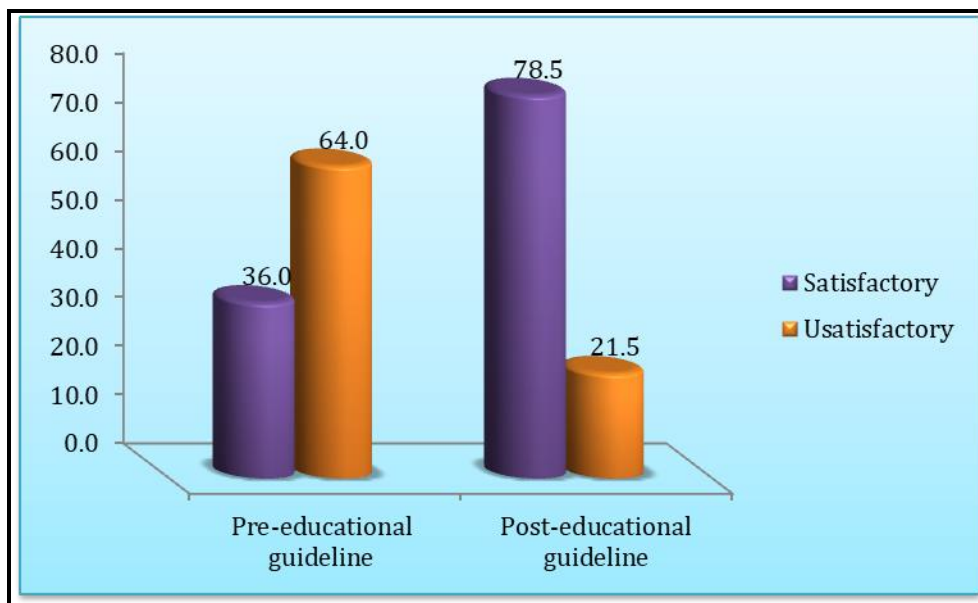


Figure (5): Percentage distribution of family caregivers regarding their total practices level pre and post educational guidelines (n=200).

Table (6): Frequency distribution of family caregivers regarding total burden of disease dimensions pre and post educational guidelines (n=200).

Items	Pre- educational guidelines						Post- educational guidelines						X <sup>2</sup>	P-value
	High		Moderate		Low		High		Moderate		Low			
	No	%	No	%	No	%	No	%	No	%	No	%		
Physical	160	80.0	40	20.0	0	0.0	100	50.0	50	25.0	50	25.0	46.95	0.000**
Psychological	160	80.0	30	15.0	10	5.0	77	38.5	60	30.0	63	31.5	77.54	0.000**
Social	130	65.0	40	20.0	30	15.0	75	37.5	70	35.0	55	27.5	30.29	0.000**

\*\*Highly significant P<0.001

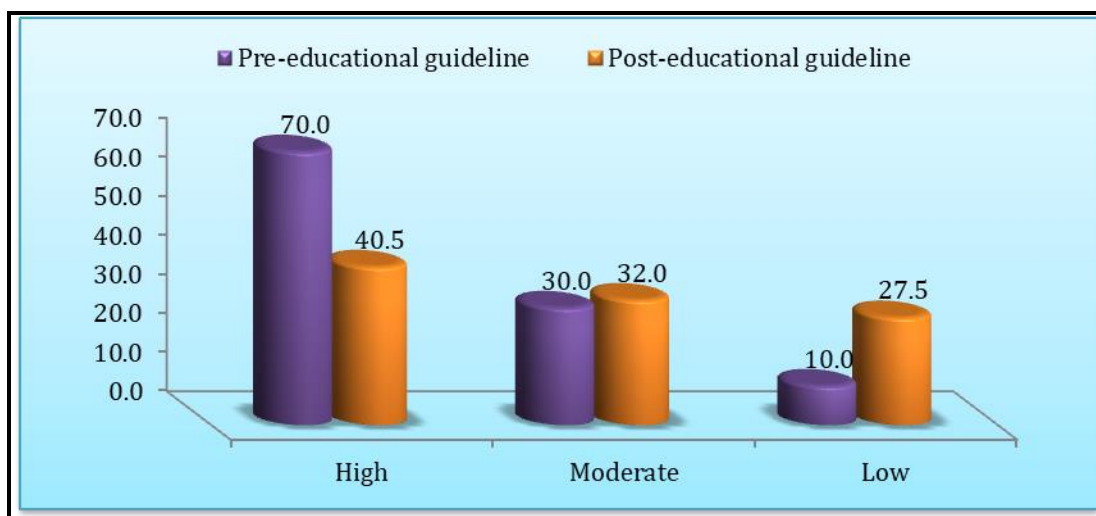


Figure (6): Percentage distribution of family caregivers regarding their total burden level pre and post educational guidelines (n=200).

**Table (7): Correlation matrix between total knowledge, total practices, and total burden of care among family caregivers for elderly cancer patients pre and post educational guidelines (200).**

Items	Pre- educational guidelines			Post- educational guidelines			
	Total knowledge	Total practices	Total burden of care	Total knowledge	Total practices	Total burden of care	
Total knowledge	r	1	.136	-.627	1	.079	.502
	p-value		.055	.000**		.264	.000**
Total practices	r	.136	1	.311	.079	1	.739
	p-value	.055		.000**	.264		.024*
Total burden of care	r	-.627	.311	1	.502	.739	1
	p-value	.000**	.000**		.000**	.024*	

\*\*Highly significant  $P < 0.001$ \*Significant  $p < 0.05$ Insignificant  $p > 0.05$ 

**Table (1):** Shows that; 55% of the studied family caregivers aged from 30-40 years old with Mean  $\pm$  SD 38.95 $\pm$ 5.41, and 62% of them were female. 35.5% of them were secondary education. While 17% of them had university education. 34% of them didn't work. 83.5% of them their income not enough. Also, 55.5% of them were daughter. 91.5% of them living in the same place of the patient and 57% caring the elderly patients 2<3times daily.

**Table (2):** Show that; 59.5% of the studied patients 60<75 years old with Mean  $\pm$  SD 63.52 $\pm$ 7.41. 78.5% of them were living in rural area. 70.5 % of patients were male. 49.5% of them were widowed, and 50 % of them were illiterate and 48% not work. Also, 89 % of them their income not enough.

**Figure (1):** Illustrates that; 59.5% of the studied patients were dependent on caregivers, and 27% of them were partially dependent on caregivers. While 13.5% of them were independent on caregivers.

**Figure (2):** Illustrates that; 35.5% of the studied patients had lung cancer, and 27% of them had prostate cancer. While 4.5% of them had bladder cancer.

**Table (3):** Illustrates that; 70% of studied patients have the disease with duration less than 3years with using chemotherapy in treatment. 84.5% have co-morbid diseases 47.3% of them had diabetes mellitus, while 59.0% of them have not any operation during the previous years.

**Table (4):** Shows that; 7.5% of studied family caregivers had correct and incomplete answer regarding causes of cancer, high risk group and dangerous symptoms that require going to the doctor's pre-educational guideline compared to 50%, 40%, 42.5% post educational guidelines respectively. Also, there were high statistically significant relation between total knowledge of the studied family caregivers pre and post educational guidelines ( $p < 0.001$ ).

**Figure (3):** Illustrated that; 80% of studied family caregivers, their knowledge was acquired from the

physician, and 45% them their knowledge was acquired from nurses. 23.5% of them were acquired their knowledge from mass media. While only 16.5%, 14% of studied family caregivers gain their information from family/friends and special reading respectively.

**Figure (4):** Illustrates that; 7.5% of the studied family caregivers had good knowledge about cancer pre-educational guidelines increased to 47% post educational guideline. While 35% of them had poor knowledge about cancer pre-educational guidelines decreased to 13% post educational guideline.

**Table (5):** Shows that; 69% of studied family caregivers unsatisfactory with follow up with the elderly patients with cancer pre-educational guidelines decreased to 41% post educational guidelines. While 31% of studied family caregivers satisfactory with nutrition of elderly patient with cancer increased to 59% post educational guidelines. As regard management of symptoms 38.5% satisfactory with management of infection preprogram increased to 68% post educational guidelines. There was high statistically significant relation between pre and post educational guideline regarding family caregivers' practices and management of symptoms ( $p < 0.001$ ).

**Figure (5):** Reveals that; 36% of the studied family caregivers had satisfactory practices score regarding to care of their cancer patients' pre-educational guidelines increases to 78.5% post educational guidelines. While 64% of them had unsatisfactory practices score pre-educational guidelines decreased to 21.5% post educational guidelines.

**Table (6):** Illustrates that; 80% of studied family caregivers had high physical and psychological burden of care pre-educational guidelines decreased to 25%, 30% post educational guidelines respectively. While 65% had high social burden of care pre-educational guideline decreased to 37.5% post educational guideline. There was high statistically significant relation regarding studied caregiver

regarding total burden of disease dimension pre and post educational guidelines.

**Figure (6):** Illustrates that; 70% of studied family caregivers had high total burden of care pre-educational guidelines decreased to 40.5% post educational guidelines. While only 10% had low total burden of care pre-educational guidelines increased to 27.5% post educational guidelines.

## Discussion

Cancer is considered the third cause of death worldwide and that also with an increasing ratio of patients. Although the use of latest technology has stood in the favor of better prognosis but still improvement is needed. It does not only make the patient to suffer but the family members of the patients and caregivers also suffer. So that, the cancer patients and caregivers need training on the management of the symptoms and best means of coping with the disease (WHO, 2021).

Family caregiver burden is defined as a negative reaction to the impact of providing care on the caregivers social, occupational, and personal roles. For caregivers of cancer patients, caregivers' burden was heavier for those who were younger, male single, and primary school education or below (Swartz & Collins, 2019).

According to demographic characteristics of the studied family caregivers, the current study revealed that; the studied family caregivers aged from 30-40 years old with Mean  $\pm$  SD 38.95 $\pm$ 5.41, and around two thirds of them were female. Regarding to educational level; One third of them were secondary education. While less than one fifth of them had university education. More than one third of them didn't work. Most of them their income not enough. Also, more than half of them were daughter. Majority of them living in the same place of the patient and more than half of them caring their elderly patients with cancer, 2<3times daily (Table 1).

These results supported by Wenhao et al., (2021), who studied "Subjective burdens among informal caregivers of critically ill patients: a cross-sectional study in rural Shandong, China," and found that, slightly more than half of informal caregivers were female (50.90%) and unemployed (53.61%), 53.79% of family caregivers were 65 years old or younger, 59.21% had at least a junior high school education.

According to demographic characteristics of the studied cancer patients, the current study revealed that; more than half of the studied patients aged 60<75 years old with Mean  $\pm$  SD 63.52 $\pm$ 7.41 (table 2). This result in same line with Ramasubbu et al., (2020) who studied "Quality of life and the factors affecting it in adult cancer patients undergoing cancer chemotherapy in a tertiary care hospital. India" and

reported that, 40% of their patients aged more than 60 years old.

Regarding gender and marital status. The current study revealed that; less than three quarters of patients were male. Around half of them were widowed (Table 2). These results supported by Zhonghui et al., (2019), who conducted a study about "The effect of a patient education and rehabilitation program on anxiety, depression and quality of life in muscle invasive bladder cancer patients treated with adjuvant chemotherapy, in China" as reported that, 55% of their studied patients were male, and widowed. This result might be due to that male considered the first one in a family to support and provide caring for all family members.

Regarding to educational level; the current study revealed that; half of patients were read and write, and unemployed, most of them their income not enough. More than three quarters of them were living in rural area. These results contrary with IJsbrendy et al., (2019), who studied "Implementing physical activity programs for patients with cancer in current practice: patients experienced barriers and facilitators in the Netherlands" as reported that (41.2%) of their studied patients had a university education, enough income and were living in rural area respectively. This might be due to socioeconomic position (SEP) is an important contextual factor in the Stress Process Model of caregiving. However, the basic assumption that low SEP is associated with greater caregiver burden has so far lacked empirical support.

Regarding studied patients' dependency level, the current study revealed that; less than two thirds of the studied patients were dependent on caregivers, and more than one fifth of them were partially dependent on caregivers. While more than one tenth of them were independent on caregivers (figure 1).

These results in the same line with Williams et al., (2020), who study "Capacity to provide geriatric specialty care for older adult in community oncology practices, Canada" and found that, (60%) of their studied patients were dependent on caregivers, and (20%) of them were partially dependent on caregivers. While one tenth of them were independent on caregivers.

Regarding studied patients past medical history, the present study revealed that, less than three quarters of patients have the cancer with duration less than three years with using chemotherapy in treatment. Most of them have co-morbid diseases, less than half of them had diabetes mellitus, while more than half of them didn't have any operation during the previous years (table 3).

These result in the same line with Yesilbalkan et al., (2017), who studied "cancer pain: knowledge and

experiences from the perspective of the patients and their family caregivers, turkey” as reported that, three quarters of their patients have the cancer with duration three years and majority of them received chemotherapy. But these results contradicted with **Burns et al., (2018)**, who studied “family caregiver knowledge of treatment intent in a longitudinal study of patients with advanced cancer, Australia” and found that, 33% of patients received radiotherapy.

Also, these results contradicted with **Ejaz et al., (2021)**, who studied “Grief among cancer patients: predictor of burden of care and mental health among their caregivers, Pakistan”, and found that one third of their studied patients have co-morbid diseases, more than half of them had diabetes mellitus, while more than half of them have operation during the previous years. And their cancer patients had various durations of their illness, among them 65 (26%) were diagnosed 6 months before, 67 (26.8%) had been fighting the illness since last one year and 40 (16%) were suffering from last 2 years. This might be due to chemotherapy is the first line of treatment of cancer after surgery and give good results. The current study revealed that; the studied family caregivers regarding their knowledge about cancer pre and post the educational guidelines intervention. Less than one tenth of studied caregivers had correct and incomplete answer regarding causes of cancer, high risk group and dangerous symptoms that require going to the doctors’ pre-educational guideline. Compared to half of them, two fifth of them, and more than two fifth of them respectively post educational guidelines intervention. Also, there were high statistically significant relation between total knowledge of the studied caregivers pre and post educational guideline ( $p < 0.001$ ) (**Table 4**).

These result in the same line with **De lamaza et al., (2020)**, who studied” the impact of a structured educational program for family caregivers of children with cancer on parental knowledge of the disease and clinical outcomes”, and reported that, structured education to caregivers increased all aspect level of knowledge and improved the clinical outcome of their studied sample.

Also, these results in the same line with **Belongacem et al., (2016)**, who studied” A caregivers educational program improves quality of life and burden for cancer patients and their caregivers: A randomized clinical trial” as reported that, there were high statistically significant relation between total knowledge of their studied caregivers pre and post program ( $p < 0.001$ ). This might be due to that; effect of guidelines that enhance family caregivers’ knowledge.

Regarding type of cancer. The current study revealed that; more than one third of the studied patients had

lung cancer and more than one fifth of them had prostate cancer. And one fifth of them had breast cancer. While only 4.5% of them had bladder cancer (Figure 2). These results supported by **Joshua & Irene, (2018)**, who studied” roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients: perspective from a low-income country, Oman” and found that, breast cancer (37.7%), lung cancer (2.3%), and prostate cancer (18.5%). This might be due to that; female considered the first one a family to support and provide caring for all family members.

The current study revealed that; the studied family caregivers regarding total knowledge pre and posts the educational guidelines intervention. Less than one tenth of the studied caregivers had good knowledge about cancer pre-educational guidelines intervention increased to less than one half of them post educational guidelines intervention. While more than one third of them had poor knowledge about cancer pre-educational guidelines decreased to more than one tenth post the educational guidelines (**Figure 4**).

This result supported by **El-Amin et al., (2021)**, who studied” Knowledge, attitudes, and practices of caregivers of caregivers of patient with cancer in Sudan, found that, 7% of the studied family caregivers had good knowledge about cancer pre-educational guidelines intervention increased to 30% of them post educational guidelines intervention. While one third of them had poor knowledge about cancer pre-educational guidelines intervention decreased to one tenth post the educational guidelines intervention. From the researchers point of view, this differences might be due to the effect of guidelines and reinforcement of that enhance family caregivers’ knowledge through evaluating after the guidelines.

Regarding family caregivers’ total practices level about care of their cancer patients pre and post the educational guidelines intervention; more than one third of the studied family had satisfactory practices score regarding to care of their cancer patients pre intervention increases to more than three quarters of them post intervention. While more than two thirds of them had unsatisfactory practices score pre intervention decreased to more than one fifth of them post intervention (**Figure 5**).

This finding was disagreed with **Eliana, (2017)**, who studied “caregiver burden: the burden of caring for lung cancer patients according to the cancer stage and patient quality of life, Brazil” and found that, nearly of half of their studied caregivers had satisfactory practices score regarding to care of their cancer patients pre intervention increased to more than three quarters of them post intervention. While



more than half of their studied caregivers had unsatisfactory practices score pre intervention decreased to more than one fifth of them post intervention. From the researchers point of view, this differences might be due to the effect of guidelines and reinforcement of that enhance family caregivers' practices through evaluating after the guidelines.

The current study revealed that; studied family caregiver regarding their total practices and management of symptoms, more than two thirds of studied caregivers unsatisfactory with follow up with the elderly patient with cancer pre-educational guidelines intervention; decreased to more than two fifth of them post educational guidelines intervention. While less than one third of studied caregivers satisfactory with nutrition of elderly patient with cancer increased to more than one half of them post educational guidelines intervention (table 5).

These result in the same line with **Odom & Wahnefried, (2021)**, who studied the self-care practices of family caregivers of persons with poor prognosis cancer: differences by varying levels of caregiver well-being and preparedness in US, and found that, two thirds of their studied caregivers unsatisfactory with follow up with their elderly patient with cancer pre-educational guidelines intervention; decreased to less than two fifth of them post educational guidelines intervention. While less than one third of their studied caregivers satisfactory with nutrition of elderly patient with cancer increased to more than one half of them post educational guidelines intervention.

As regard management of symptoms less than two fifths of the studied family caregivers satisfactory with management of infection pre-educational guidelines intervention increased to more than two thirds of them post educational guidelines intervention. There was high statistically significant relation between pre and post program regarding caregivers' practices and management of symptoms ( $p < 0.001$ ) (table 5). This result agreed with **Sabo and Chin (2021)**, who studied "Self-care needs and practices for the older adult caregiver: An integrative review US, and found that, two fifths of their studied caregiver satisfactory with management of infection preprogram increased to less than two thirds of them post educational guidelines intervention. There was high statistically significant relation between pre and post program regarding caregivers' practices and management of symptoms ( $p < 0.000$ ).

Regarding the studied family caregivers total burden level pre and post educational guidelines intervention. The current study revealed that; less than three quarters of the studied caregivers had high total burden of care pre intervention decreased to

more than two fifth of them post the educational guidelines intervention. While, only one tenth of them had low total burden of care pre intervention increased to more than one fifth of them post intervention (**Figure 6**).

These findings agreed with **Onyeneho & Hesanni, (2021)**, who study "Burden of care and perceived psycho-social outcomes among family caregivers of patients living with cancer. Asia, and found that, three quarters of their studied caregivers had high total burden of care pre intervention decreased to fifth of them post intervention. While more than one fifth of them had low total burden of care pre intervention decreased to only one tenth of them post intervention.

This might be due to findings from the study suggesting that there are various levels of burden experienced by family caregivers, ranging from mild-to-severe levels. However, the study revealed that most caregivers had mild level of burden. The explanation for this is not hard to find as most people tend to shy away from expressing their views on how they feel because of their relationship with the care recipient, even though the burden exists.

Regarding total burden of disease dimension pre and post educational guidelines intervention. The current study revealed that, most of studied family caregivers had high physical and psychological burden of care pre intervention decreased to more than one fifth, less than one quarter of them post intervention respectively. While more than two thirds of them had high social burden of care pre intervention decreased to more than one third of them post intervention. There was high statistically significant relation studied caregivers regarding total burden of disease dimension pre and post intervention (**Table 6**).

From the researchers' viewpoint the previous results might be due to in general, the effects on health range from physical, psychological, economic to social health problems. The timing of entry into the caregiving role and duration of the role significantly influences the psychological well-being of the caregiver.

These finding agreed with **Oboh & Adaonfo (2017)**, who studied "Cancer informal caregivers' burden at the University college hospital, Ibadan, Nigeria. And found that, a high level of burden among caregivers of people living with cancer these result which stated that caregivers experience psychological burden (43.3%). findings which reported physical burden among 43.4% of the study population.

Regarding the correlation matrix between total knowledge, total practices and total burden of care among studied family caregivers for elderly patients with cancer pre and post educational guidelines intervention, the present study revealed that, there

were a high statistically significant correlation between total knowledge, total practices, and total burden scores of the studied family caregivers for elderly patients with cancer ( $P < 0.001$ ) (Table 7).

This result supported by El-Amin et al., (2021), who studied "Knowledge, attitudes, and practices of caregivers of caregivers of patient with cancer in Sudan. And found that, there were a high statistically significant correlation between total knowledge, total practices, and total burden scores of their studied caregivers for older adult patients with cancer ( $P < 0.000$ ). This might be due to; the burden of family caregivers of cancer patients might vary according to the illness stage and could depend on factors related to the patient condition.

### Conclusion

According to the results of this study, the educational guideline had a substantial impact on family caregivers' knowledge and practices in older cancer patients. The findings of this study correctly support the diverse burden of care experienced by family caregivers; ranging from negative health effects to physical, psychological, and social burden, less than three quarters of the studied family caregivers had high total burden of care pre intervention decreased to more than two fifth of them post the educational guidelines intervention. While, only one tenth of them had low total burden of care pre intervention increased to more than one fifth of them post intervention. The burden of caring for family caregivers was significantly reduced. there was a high statistically significant correlation between total knowledge, total practices, and total burden scores of the studied family caregivers for elderly patients with cancer ( $P < 0.001$ ).

### Recommendations

1. Based on the findings of this study, therefore recommend a routine assessment of all family caregivers of patients living with cancer by health-care providers on outpatient and in-patient basis, using a standard instrument.
2. Coping strategies, and how to do a self-assessment of family caregivers' challenges can be investigated.
3. Furthermore, development of mobile applications that are equipped with adequate information on what caregiving entails how to manage different symptoms or effects associated with caregiving.
4. Further studies should be provided to determine what factors increase family caregivers burden of care and impact their quality of life.
5. This educational guideline should be applied on a wide range.
6. Support from the community should be provided

to family caregivers of cancer patients.

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