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Effect of Palliative Care Awareness on Burden of Family Caregivers for Elderly Patients with Cancer

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Abstract: Background: Family caregivers face a significant burden while caring for elderly patients with cancer, which can be decreased by increasing awareness about palliative care. Purpose: To determine the effect of palliative care awareness on the level of burden for caregivers providing care for elderly patients with cancer. Design: A quasi-experimental one-group pre-post-test design was used. Setting: The study was conducted at the Oncology Department of Menoufia University Hospital, Egypt. Sample: A convenience sample of 96 caregivers who were caring for elderly patients with cancer was selected. Instruments: three instruments were used (structured interviewing questionnaire, palliative care knowledge scale (PaCKS), burden scale for family caregivers (BSFC)). Results: There was a highly statistically significant increase in the mean of total knowledge score about palliative care in post-intervention 1 (11.10 \pm 1.96) and post-intervention 2 (9.93 \pm 0.55) than pre-intervention (3.75 \pm 1.50). There was a statistically significant reduction in the mean of total burden score from $56.94 \pm$ 18.42 pre-intervention to 31.88 ± 16.66 post-intervention. Conclusion: Increasing awareness about palliative care was effective and crucial in decreasing the burden of family caregivers for elderly patients with cancer, and there was a significant increase in the mean of total knowledge score about palliative care. Recommendations: Palliative nursing intervention should be an important component in the management of elderly patients with cancer, besides conventional therapy.

Keywords: Cancer, Caregiver burden, Elderly patients, Palliative care awareness.

Introduction

Cancer is a leading cause of death worldwide that accounts for one-sixth of all deaths and ten million deaths each year. Elderly patients with cancer not

only suffer from cancer itself, but also from age-related problems and comorbid acute and chronic conditions that negatively impact their physical

and social functioning. consequently, they require comprehensive care and support. Moreover, the prolonged course of cancer has turned patients' family caregivers into their main caregivers (Mohammadian et al., 2023). Cancer cases are expected to increase in Egypt due to the change in population growth and the change in demographics. The standard incidence rates for age per 100,000 reached 166.1. Projections up to 2050 indicate that the incidence of cancer in Egypt is 341.169/100,000 of the total population (Zaki et al., 2024).

Caring for patients with cancer can result in significant burden, which includes a set of reactions in the caregiver that occurs in physical, psychological and social domains, that is due to the lack of coordination and balance between the responsibilities of the caregiver to meet the patient's care needs, and other tasks and roles in social. personal, physical situations, emotional as well availability of financial resources (Karimi Moghaddam et al., 2023; Junkins et al., 2020). The negative impacts of caregiving roles are significant problems in the healthcare system, and if family care is not taken to protect the family caregivers, it affects their ability to caregiving and reduces the quality of patient care, so the caregivers themselves will become an excessive burden on the healthcare system (Karimollahi et al., 2022).

Caregivers' burdens can be decreased when elderly patients' needs are met. To respond to these needs and decrease caregivers' burdens, the caregiver should be prepared for the caregiving role (Chua et al., 2020). Caregiver preparedness is defined as perceived readiness for caregiving includes responsibilities. This caregivers' perception of their ability to care for the physical and emotional needs of care recipients, arranging services, monitoring symptoms, treatment management, and handling emergencies. Higher caregiver preparedness has been related to less caregiver burden in caregivers of patients with cancer (Karabulutlu et al., 2022).

Having well-prepared caregivers and promoting their well-being are core elements of a palliative care approach (Zomerdijk et al., 2022). Palliative care integration with oncology care early in the course of illness has myriad benefits for patients and their caregivers, including improved quality of life, reduced physical and psychological symptom burden, enhanced prognostic awareness, and reduced health care utilization (Petrillo et al., 2024). Early palliative and supportive care are important for older patients with cancer, and should be part of the standard oncological care, regardless of disease stage. In addition, in some types of cancer, early integration of palliative care has been shown to have similar effects to first-line chemotherapy (Castelo-Loureiro et al., 2023).

There are many barriers to integrating palliative care into cancer care, such as a lack of awareness and training programs about palliative care, a lack of effective communication between healthcare professionals, patients, and their caregivers, limited palliative care resources, and societal misconceptions

about palliative care that mean end-oflife care. Therefore, lowering or removing these obstacles requires raising patients' and caregivers' overall awareness of palliative care and their level of knowledge about it (Mayland et al., 2021).

Basing on this, nurses can help with increasing awareness about palliative care by training on the standards of palliative care, providing education to patient and family to dispel myths surrounding palliative care, advocating for health care policies that impact the delivery of palliative care and other essential components of care, providing leadership in community palliative care formation, and conducting palliative care research (Brant et al., 2021).

Significance of the Study:

As the world's population ages, one in six individuals will be over 65 by 2050. Aging at the biological level is caused by a build-up of cellular and molecular damage, which raises the risk of cancer. Therefore, the need to provide highquality care to older adults with cancer will increase in the coming years (Castelo-Loureiro et al., 2023). For most cancer patients, family members or friends serve as informal carers who have an important role in the homebased management of cancer and managing patients' symptoms addition to other home tasks without respite. Therefore, informal carers suffer from a high level of burden, and this negatively affects their health and well-being and thus outcomes for cancer patients (Kent et al., 2019; Gül et al., 2024).

Reducing the burden of family caregivers and improving their quality of life is one of the important goals of palliative care (Rooeintan et al., 2023). The effectiveness of palliative care measures can maintain the patient's quality of life and improve their independence by ameliorating the effects of symptoms such as fatigue, anorexia, and pain, as well as support the patient and their family caregivers (Deol et al., 2024).

The development of palliative care varies widely among Arab countries, but even in the most advanced countries, the availability of services is insufficient to meet the needs of the population given the high incidence of cancer due to a lack of national regulations and funding, shortage of resources, low public human awareness, and a lack of coordination and collaboration among palliative care experts (Al-Shamsi et al., 2022). So, it is important to conduct this study to assess the awareness of caregivers about palliative care and its effect on decreasing their burden.

Methods

Purpose:

To determine the effect of palliative care awareness on the burden of family caregivers for elderly patients with cancer

Research hypotheses:

To fulfill the current study's purpose, the following research hypotheses were generated:

• H1- There will be a significant increase in family caregivers' awareness regarding palliative care

for elderly patients with cancer postintervention compared to preintervention.

■ **H2**-There will be a significant decrease in family caregivers' burden post-intervention compared to pre-intervention.

Research Design:

A quasi-experimental design (one-group pretest-posttest design) was utilized.

Setting:

The study was conducted at the Oncology Department of Menoufia University Hospital, Egypt.

Sample:

A convenience sample of 96 caregivers who were caring for elderly patients with cancer.

Sample size calculation:

The sample size was determined by using the Taro Yamane formula (Yamane, 1967).

 $n = N / 1 + N (e)^{2}$

 $N \rightarrow$ total number of population is (436)

 $n \rightarrow$ sample size

 $e \rightarrow \text{allowable error (0.09)}$

 $1 \rightarrow$ constant value

Sample size = $436 / (1+436) \times (0.09)^2$

= 96

Instruments:

Three instruments were used in the current study.

Instrument one: Structured interviewing questionnaire:

The researcher developed this instrument after reviewing the related literature (Abd EL-Moatamed et al., 2022). It was used to obtain personal

and medical data about elderly patients with cancer. Also, the personal data of family caregivers. It included three parts: -

- Part 1: Socio-demographic data of the elderly patients: including age, gender, marital status, level of education, number of family members, and monthly income.
- Part 2: Medical history of the elderly patients: including diagnosis, duration of cancer disease, dependency level, treatment used for cancer, and side effects of treatment.
- Part 3: Socio-demographic data of the family caregivers: including age, gender, marital status, level of education, working condition, kinship, monthly income, place of residence, living in the same place, duration of care for a cancer patient, and receiving health education and training regarding palliative care or not.

Instrument two: Palliative Care Knowledge Scale (PaCKS)

It was designed by Kozlov et al., (2017) to assess caregivers' level of knowledge about palliative care. It was translated into Arabic by the researcher and reviewed by an English-Arabic language specialist.

Scoring system:

It has 13 true/false questions, scored as 1 for a correct response and 0 for an incorrect response. Total scores range from 0:13. A score of 0:6 was considered a weak level of knowledge, 7:10 a moderate level, and 11:13 a high level of knowledge.

Instrument three: Burden Scale for Family Caregivers (BSFC)

It was designed by Gräsel et al., (2003) to measure the burden experienced by family caregivers. It is the most important caregiver-related variable for the care of chronically ill elderly at home. It consists of 28 items. The scale was in the form of a 4-point Likert scale (strongly agree, agree, disagree, strongly disagree)

Scoring system:

The responses to the 28 statements of the BSFC are rated according to the following scheme:

- A. For the statements numbered 1, 6, 8, 9, 11, 14,15, 17, 19, 22, and 28, they are scored as follows: Strongly agree = 0, Agree = 1, Disagree = 2, Strongly disagree = 3
- **B.** For the remaining statements numbered 2, 3, 4, 5, 7, 10, 12, 13, 16, 18, 20, 21, 23, 24, 25, 26, and 27, the scores are reversed as follows: Strongly agree =3, Agree =2, Disagree = 1, Strongly disagree = 0

 The maximum score of the Burden Scale for Family Caregivers is "84". It is categorized as follows: Zero-41 is considered none to mild burden, 42-55 is considered moderate burden, 56-84 is considered severe burden.

Validity of the instruments:

The data collection instruments were tested for face and content validity by a jury of five experts for accuracy, clarity, and completeness, and their recommended modifications were taken into consideration.

Reliability of the instruments:

The internal consistency approach was used to assess the instruments' reliability. The reliability proved to be high with a Cronbach alpha coefficient =0.94 for the instrument II (Palliative Care Knowledge Scale (PaCKS)) and 0.91 for instrument III (Burden Scale for Family Caregivers (BSFC)).

Pilot study:

A pilot study was carried out on 10% of the total sample (n=10) to test the clarity, feasibility, and applicability of the instruments. It was also helpful to estimate the time needed to fill out the study instruments. No modifications were made, and the pilot study sample was not included in the study sample.

Ethical Considerations:

- An approval sheet was obtained from the Ethical Research Committee of the Faculty of Nursing, Menoufia University (Study No:1000/12/6/14/23 on 6/12/2023)
- An official letter was obtained from the dean of the Faculty of Nursing and directed to the administrator of the study setting to permit data collection, procedure, process, and gain support. It included the purpose of the study and the methods of data collection.
- Written informed consent was obtained from each participant of the study after being informed about the purpose, procedure, benefits, nature of the study, and their right to voluntarily withdraw from the study at any time without penalty. The participants were assured that their

data would be kept secret and used only for research purposes.

Data collection procedure:

Data was collected in the period from the beginning of December 2023 to the end of March 2024.

- Instruments of data collection and an educational booklet were developed after reviewing the relevant literature, including books, magazines, articles, periodicals, and websites. In addition, the instruments were tested for validity and reliability.
- The researcher introduced herself to the family caregivers and then explained the purpose and nature of the study to gain family caregivers' cooperation.
- Written informed consent had been obtained from each participant and they were assured of close confidentiality of data.
- Each participant was interviewed individually in the oncology department before intervention to assess the level of knowledge of family caregiver about palliative care and the level of burden. It took about 20-25 minutes.
- After that, the researcher provided intervention in 2 sessions (one session/ week)
- ➤ First session took about 30 minutes: Objectives of this session: -at the end of this session, family caregivers should be knowledgeable about cancer (define, list signs and symptoms of cancer, discuss treatment methods of cancer, as well as the side effects of treatment).

➤ Second session took about 40 minutes:

Objectives of this session: -at the end of this session, family caregivers should be knowledgeable about palliative care (define, list goals of palliative care, identify suitable time to start palliative care, palliative care team and palliative care beneficiaries, discuss of role of palliative care in relieving physical and psychological symptoms of elderly patients with cancer).

- Each session ended with a summary of its content and feedback from the caregiver.
- Family caregivers were asked to recall their feedback about palliative care (immediate posttest of knowledge) for about 10- 15 minutes.
- The researcher visited the oncology department for 2 to 3 days a week and implemented the intervention for caregivers individually or in groups (5-6 caregivers).
- Following the implementation of the intervention, family caregivers were given a printed copy of the palliative care (colored booklet) and were instructed to practice these interventions to decrease cancer treatment side effects in their elderly patients with cancer.
- Posttest was done using the study instruments to evaluate the effect of intervention immediately (for knowledge about palliative care), after intervention, and one month from the immediate posttest (for knowledge about palliative care and caregiver burden).

Statistical analysis:

Data was entered and analyzed by using the SPSS (Statistical Package for Social Science) statistical package version 26. For qualitative data, the numbers and percentages were calculated and represented in the form of frequency distribution tables. The quantitative data were represented by mean (\bar{x}) and standard deviation (SD).

The used tests were repeated measures ANOVA (within-subjects ANOVA), for normally distributed quantitative variables, to compare between three or more related means, Wilcoxon Signed Ranks Test, for not normally distributed quantitative variables, to compare between two periods.

Significance of the results: -

- Statistically significant p < 0.05
- Highly statistically significant p < 0.001
- Not significant, P < 0.05

Results:

Table 1: demonstrates the sociodemographic characteristics of the family caregivers. As shown, the mean age of the family caregivers is $44.86 \pm$ 13.25, and 83.3% of them are females. More than three-quarters of family caregivers (78.1%) are married, and nearly half of them (47.9%) have a secondary education. Also, the majority of them (81.3%) don't work, and 90.6% don't have enough income. Regarding to their kinship, sons/daughters are more common (60.4%), 75% of them live in the same place, and 84.4% of them are rural residents. Added to that, more than two-fifths of them (44.8%)

cared for a cancer patient for one to less than three years.

Table 2: represents the sociodemographic characteristics of the elderly patients with cancer. As shown, the mean age of the elderly patients with cancer is 68.37±7.37 years old, and 78.1% of them are females. More than two-thirds of them (74%) are married, with a mean number of their family members of 4.92 ± 1.43 . Regarding their education, more than half of them (53.1%) are illiterate. Also, three-quarters of them (75%) don't have enough income.

Fig. 1: shows the distribution of the elderly patients with cancer regarding to their dependency level. Nearly three-quarters of the elderly patients (73%) are dependent, while about one-quarter of them (23%) are partially dependent, and only 4% of them are independent.

<u>Fig. 2</u>: clarifies the distribution of burden categories among family caregivers pre-intervention. As shown, nearly two-thirds of family caregivers (63.50%) have a severe burden, while about one-fifth of them (19.80%) have a moderate burden, and 16.70% of them have a mild burden pre-intervention.

<u>Table 3</u>: reveals the distribution of knowledge categories among family caregivers pre- and Post-intervention. As shown, there is a significant increase in the mean of total knowledge score in post intervention 1 (11.10 \pm 1.96) and post intervention 2 (9.93 \pm 0.55) than pre intervention (3.75 \pm 1.50) with a highly statistically significant difference (p < 0.001**).

<u>Table 4</u>: shows the distribution of burden categories among family caregivers pre- and post-intervention.

As shown, 63.5% of family caregivers have a severe burden pre-intervention, while this percentage decreased to 12.5% post-intervention. Also, there is a significant reduction in the mean of

total burden score from 56.94 ± 18.42 pre-intervention to 31.88 ± 16.66 post-intervention with a highly significant difference between pre- and post-test (p < 0.001**).

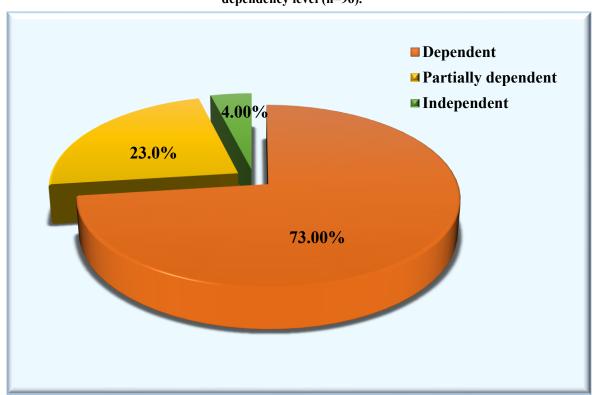
Table (1): Distribution of socio-demographic characteristics of the family caregivers (n=96).

Socio-demographic Characteristics	No.	%
Age (years)		
Mean ± SD.	44.86 ± 13.25	
Gender	_	
Male	16	16.7
Female	80	83.3
Marital status		1
Single	16	16.7
Married	75	78.1
Widowed	2	2.1
Divorced	3	3.1
Level of education	•	•
Illiterate	15	15.6
Primary education	14	14.6
Secondary educationaaaaaa	46	47.9
High education	21	21.9
Working condition		
Work	18	18.7
Not work	78	81.3
Kinship		
Husband / wife	19	19.8
Son / daughter	58	60.4
Brother / sister	18	18.7
Grandson	1	1.1
Monthly income		1
Not enough	87	90.6
Enough	9	9.4
Place of residence	1 04	
Rural	81	84.4
Urban	15	15.6
Living in the same place with the elderly		
Yes	72	75.0
No	24	25.0
Duration of care for a cancer patient		T
<1	25	26.0
1<3	43	44.8
3≤	28	29.2

Table (2): Distribution of socio-demographic characteristics of the elderly patients with cancer (n=96).

Socio-demographic Characteristics	No.	%	
Age (years)	•		
Mean ± SD.	68.37± 7.37		
Gender	•		
Male	21	21.9	
Female	75	78.1	
Marital status	•		
Single	0	0.0	
Married	71	74.0	
Widowed	23	24.0	
Divorced	2	2.0	
Level of education	-	l .	
Illiterate	51	53.1	
Primary education	14	14.6	
Secondary education	21	21.9	
High education	10	10.4	
Monthly income			
Not enough	72	75.0	
Enough	24	25	
Number of family members			
Mean ± SD.	4.92 ± 1.43		

Figure (1): Percentage distribution of the elderly patients with cancer regarding to their dependency level (n=96).



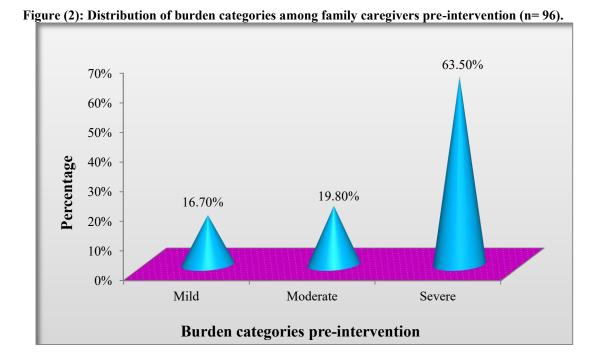


Table (3): Distribution of knowledge categories among family caregivers pre and post-intervention (n=96).

No.	Knowledge categories	Pre- intervention		Post- intervention 1		Post- intervention 2		P.value
	8 8	No.	%	No.	%	No.	%	
1	Weak (0-6)	88	91.7	7	7.3	0	0.0	
2	Moderate (7-10)	8	8.3	11	11.5	88	91.7	
3	High (11-13)	0	0.0	78	81.2	8	8.3	P < 0.001**
Total k Mean :	nowledge score ± SD.	3.75 ±	1.50	11.10 ±	1.96	9.93	± 0.55	

^{**:} High significance

Test: Repeated measures ANOVA (within-subjects ANOVA)

Table (4): Distribution of burden categories among family caregivers pre and post-intervention (n=96).

NI.	Burden categories	Pre-intervention		Post-intervention		ъ .
No.		No.	%	No.	%	P.value
1	Mild (0-41)	16	16.7	67	69.8	z= 8.512 ^b
2	Moderate (42-55)	19	19.8	17	17.7	
3	Severe (56-84)	61	63.5	12	12.5	P < 0.001**
Total but Mean	rden score ± SD.	56.94 =	± 18.42	31.88	± 16.66	

^{**:} High significance

Test: Wilcoxon Signed Ranks Test

Discussion

Cancer poses a significant public health challenge, ranking as the second leading cause of death globally. An estimated 19 million new cancer cases emerged worldwide in 2020 (Siegel et al., 2023). With the increasing incidence and survival rate of cancer, more people are living with cancer, which increases the responsibilities of informal caregivers, resulting in a significant caregiver burden, depression, and low quality of life. This can be avoided by the health application of palliative interventions (Bisht et al., 2023).

Cancer patients often receive palliative care, which focuses on improving their quality of life by managing symptoms and providing emotional support throughout their treatment journey. The primary aim of palliative care in cancer patients is to enhance the lives of both patients and their families by alleviating pain, addressing biopsychosocial and mental challenges (Cubukcu et al., 2024). Therefore, this study was conducted to determine the effect of palliative care awareness on the burden of family caregivers for elderly patients with cancer.

In relation to the distribution of the elderly patients with cancer regarding to their dependency level, the present study showed that seventy-three percent of them were dependent, while twenty-three percent of them were partially dependent, and only four percent of them were independent. This result was similar to Moursi & Sabry, (2022); they mentioned that 59.5% of patients were dependent, while more than one quarter of them (27%) were partially dependent, and only one tenth of them were independent. In

the same line, Williams et al., (2020) studied "Capacity to provide geriatric specialty care for older adults in community oncology practices, Canada". And found that sixty percent of their studied patients were dependent on caregivers, and twenty percent of them were partially dependent on caregivers, one tenth of them independent. This might be related to most of elderly patients with cancer suffer from an increase in dependency level due comorbidities, to frailty, and deconditioning that result from a decline physical, physiologic, psychological processes due to cancer. Regarding to the knowledge of palliative

care among family caregivers, the present study indicated that there was a significant increase in the mean of total knowledge score in post-intervention 1 and post-intervention 2 than preintervention. Thus, these results reflect the effectiveness of palliative care increasing awareness in family caregivers' knowledge regarding palliative care for elderly patients with cancer, and these findings provide support to the current research hypothesis research numbered one. So, the hypothesis was accepted.

This study result was consistent with Abd EL-Moatamed et al., (2022), reported that less than half of the studied caregivers had a poor total level of knowledge before the educational guidelines implementation, which decreased to less one one-fifth after the educational guidelines implementation. Also, this current study finding was similar to that of Shah, et al., (2020), who studied "Perceptions, knowledge and

attitudes towards the concept and approach of palliative care amongst caregivers: a cross-sectional survey in Karachi, Pakistan". They mentioned that more than half of the caregivers had enhanced understanding of the palliative care approach post-intervention.

Similarly, this study result was supported by Seymour, (2018), who studied "The Impact of Public Health Awareness Campaigns on the Awareness and Quality of Palliative Care, Canada". He found that raising public awareness in palliative care was effective in increasing knowledge categories about palliative care for elderly patients with cancer. Furthermore, the present study result came in agreement with Younis & Hamdan, (2024), who studied "Status and Predictors of Medical Students' Knowledge and Attitude towards Palliative Care in Jordan: a crosssectional study ". They reported that there was a significant difference between those who were exposed to palliative care awareness and those who were not (t = -6.33, p < 0.001), with a higher mean score of those exposed to palliative care courses those who were not. consistency in results is due to the effect of palliative care awareness in increasing knowledge about palliative care by correcting the misconception about palliative care.

Concerning the distribution of burden categories among family caregivers, the present study showed that sixty-three percent of family caregivers had severe burden pre-intervention, while this percentage decreased to twelve percent post-intervention. Also, there was a significant reduction in the mean of total burden score post-intervention than pre-intervention. Thus, these results reflect

the effectiveness of palliative care awareness in decreasing the burden of family caregivers for elderly patients with cancer, and these findings provide support to the current research hypothesis numbered two. So, the research hypothesis was accepted.

This study result was supported by Cubukcu et al., (2024), who studied "Effect of Education on Symptom Management and Control in Cancer Patients Receiving Palliative Care". The educational intervention positively impacted symptom management and family needs. Optimizing symptom control would greatly benefit palliative care patients and their caregivers, which leads to a reduction of burden.

Also, this current study finding was similar to that of Supaporn et al., (2023), who studied "Effectiveness of Homebased Palliative Care Programmes for Older People and their Family Caregivers in Thailand ". They mentioned that the program significantly improved caregiving burden and quality of care in Thai older people and their family caregivers. Furthermore, this study was in the same line with Schulman-Green et al., (2023), who studied" Improving Breast Cancer Family Caregivers' Palliative Care Literacy: A pilot Randomized Trial". They illustrated that intervention participants improved their palliative care literacy and family engagement, reduced and caregiver uncertainty burden, increased competence and personal gain, and had more goals of care conversations over time. This consistency in results is due to the effect of palliative care awareness in decreasing the burden of family caregivers for elderly patients with cancer, by the fact that relieving the side

effects of the disease and it is treatment; improving the quality of life of patients; when their quality of life is improved, their caregivers feel less burden.

Conclusion

Increasing awareness about palliative care was associated with decreasing burden of family caregivers for elderly patients with cancer, and there was a significant increase in the mean total knowledge score of family caregivers about palliative care.

Recommendations

Based on the study findings, the following recommendations are proposed:

- Educational sessions about palliative care using a colored illustrated booklet in the management of elderly patients with cancer, besides conventional therapy.
- Further studies using a larger sample for further confirmation and generalizability of the results.

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