

# Effect of a Palliative Care Support Program for Family Caregivers of End-Stage Renal Disease Terminally Ill Geriatric Patients

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## ABSTRACT

**Background:** Palliative care can help to enhance the quality of life of the terminally ill geriatric patients. Supporting the family in caring for elderly patients with end-stage renal diseases (ESRD) and are on hemodialysis is the key part of palliative care. **Aim:** The aim of the study was to evaluate the effect of a palliative care support program for family caregivers of ESRD terminally ill geriatric patients. **Subjects and methods: Research design:** Quasi-experimental research design was used (one-group pretest–posttest). **Setting:** Dialysis unit in Al Moassat Alexandria University Hospital and family caregivers/geriatric patients' own homes. **Subjects:** Convenience sample of 45 family caregivers of geriatric patients with ESRD. **Tools of data collection:** (1) Family caregivers' socio-demographic and clinical data-structured interview schedule; (2) health profile of geriatric patients with ESRD-structured interview schedule; (3) Palliative Care Knowledge Scale; (4) Family caregivers' practices of palliative-care-structured interview schedule. **Results:** Knowledge and practices of the majority of the family caregivers have improved after the implementation of the study intervention than before the intervention, and the difference is statistically significant ( $p < .001$ ). **Conclusion:** The palliative care support program proved to be effective in improving knowledge and practices of the family caregiver of terminally ill geriatric patients with ESRD. The study hypothesis was supported by the study data. **Recommendations:** Inclusion of the study developed a palliative care support program in the plan of care for terminally ill geriatric patients with ESRD in all relevant healthcare settings.

**Keywords:** end-stage renal disease, family caregivers, geriatric patients, palliative nursing care, support program

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## INTRODUCTION

Because of the dramatic increases in both life expectancy and the length of time living with chronic conditions, there has been an increasing emphasis on providing supportive care during chronic and life-limiting terminal illness at the end of life (EOL) [1]. Most of the older people prefer to be cared for by their family members in their EOL [2]. With the aging of the population, the demand for EOL care will continuously increase. Family caregiving

is essential to the well-being of patients with serious illness in the community. Family members perform essential tasks, such as helping with day-to-day chores, coordinating care among different healthcare providers, and providing medical care [3].

Choosing palliative care at a proper time can help maintain the patient's dignity and enhance the quality of life of the elderly patient [4]. Palliative care is patient- and

family-centered care that optimizes the quality of life by anticipating, preventing, and treating suffering. It is provided throughout the continuum of illness and it includes care at the EOL. The scope of palliative care is broad and involves addressing physical, intellectual, emotional, social, and spiritual needs, and facilitating patient's choice, autonomy and access to information [1, 5]. Purely palliative care may be elected when previously curative treatment is no longer effective such as end-stage cancer, end-stage heart diseases, end-stage renal diseases (ESRD), Parkinson's disease, and Alzheimer's disease [5, 6]. Palliative care is not restricted to any special place. Ideally, this care should be available to people where appropriate, which may range from the person's home to specialized hospices [6].

Older people of 60 years of age and above with ESRD newly doubled in the last 25 years. ESRD is associated with high mortality rate, nearly twice those of patients with other serious chronic diseases, including cancer, congestive heart failure, and stroke [7, 8]. There are significant barriers to adequate palliative care for patient with ESRD and on hemodialysis. These patients have a lack of access to supportive care, lack of awareness, lack of nurses' knowledge, lack of family support, and financial problems [9–11].

Since patient suffering and caregiver well-being are closely intertwined, interventions have the potential to reduce distress in both patient and caregivers [3]. Therefore, the attention should be focused on family caregiver needs and to develop the knowledge necessary to meet demands of EOL health care in the home [2]. However, although the support of family caregivers has been a central tenet of palliative care for decades, few of these interventions have been developed for family caregivers

of patients with ESRD at their EOL [3, 12, 13].

There is no single right plan for the EOL care. The best plan is the one that reflects the individual's values, beliefs, knowledge, and needs [6]. Palliative nursing care support program should include aggressive and comprehensive symptoms management, open and honest communication about prognosis, treatment, and the dying process. In addition to the ongoing discussion about patients' and family caregivers' goals of care, psychological and spiritual support for patients and their families should be addressed. It should also include bereavement services [1, 9].

The care of family members who care for terminally ill patients in the home must be one of the priorities of the community and gerontological nursing professionals who face changes in the social context in the community such as the rising desire to die at home, and the health system (EOL care, interdisciplinary approaches, and continuity in care, among others) [2, 6]. The gerontological and the community health nurses need to recognize the physical and emotional needs of all the caregivers working with a dying person and their loved ones. Providing emotional support to family caregivers can help them maintain the high level of energy and well-being needed to meet the various physical and psychosocial needs of the terminally ill geriatric patients with ESRD [2, 5, 14].

### **SIGNIFICANCE OF THE STUDY**

Geriatric patients comprise the most growing population initiating hemodialysis; this therapy may not improve survival in these patients. Geriatric patients on hemodialysis carry a heavy burden of unrelieved suffering, with many having inadequately controlled pain, sleep disturbance, fatigue, pruritus, depression, severe cognitive impairment,

and a shortened life expectancy. At the same time, the family caregivers of these patients are required to provide care and to manage these problems. Unfortunately, family caregivers are often not equipped to manage patients' needs, and are therefore not likely to be met at home. Thus patients and their families are likely to benefit from a palliative care support program. It will improve the quality of life of these patients and their families in facing the problems associated with ESRD which is a life-threatening illness [9, 10]. Having the required knowledge and practices helps to ease difficulty in caring for older people with renal disease at home, decrease the suffering and the burden of the caregiving [10, 11, 15].

### **Aim of the Study**

The aim of this study was to evaluate the effect of a palliative care support program for family caregivers of ESRD terminally ill geriatric patients.

### **Research Hypothesis**

It was hypothesized that family caregivers of terminally ill geriatric patients with ESRD who receive a palliative care support program exhibit higher level of knowledge and practices than before it.

## **SUBJECTS AND METHOD**

### **Research Design**

Quasi-experimental research design was used (one-group pretest–posttest).

### **Study Setting**

The study was conducted in the dialysis unit of Al Moassat Alexandria University Hospital and the family caregivers/geriatric patients' own homes. Al Moassat University Hospital is located at Abo Quir Street. The hospital consists of floor floors. It provides services for patients in all medical and surgical specialties. It includes inpatient, outpatient, and four intensive care units: one general, one for bone marrow

transplantation, one for kidney transplantation, and one for liver transplantation. Also, it includes special units, namely bone marrow transplantation, kidney transplantation liver transplantation and kidney dialysis. As for kidney dialysis unit, it consists of five rooms; two rooms for patients who are free from hepatitis (negative), one room for hepatitis C positive, and two rooms for hepatitis B positive with 34 beds and 34 hemodialysis machines. The working hours in the unit are divided into three shifts: morning shift, afternoon shift, and evening shift. Each shift includes four hours every day from Saturday to Thursday. There are 12 nurses available in the morning shift and 5 nurses in the other shifts with one working physician each shift.

### **Study Subjects**

A convenience sample of 45 family caregivers of geriatric patients with ESRD, who live with them, provide direct care, and able to communicate.

### **Tools of Data Collection**

#### ***Tool (I) Family Caregivers' Socio-demographic and Clinical Data-Structured Interview Schedule***

It includes age, sex, religion, marital status, occupation, level of education, income, address, telephone number, needs, worries, and difficulties and duration of caregiving.

#### ***Tool (II): Health Profile of Geriatric Patients with ESRD-Structured Interview Schedule***

It includes medical history, duration of the disease, presence of health problems related to hemodialysis, physical disability, type of medication used, and access to medical care.

#### ***Tool (III): Palliative Care Knowledge Scale (PaCKS)***

This scale was developed by "Kozlov E" in 2016 [16] to assess knowledge related to

palliative care. PaCKs include 13 statements: response of the caregivers is true, false, and I do not know. The statements of the PaCKs include goals of a palliative care, members of the palliative care team, system-related components of palliative care, timing of palliative care, and symptoms that palliative care address. The PaCKs also could be used to understand knowledge gaps and thus guide important educational interventions with patients, family members, and healthcare personnel. The reliability of this tool is 0.71.

#### **Tool (IV): Family Caregivers' Practices of Palliative-Care-Structured Interview Schedule**

This tool was developed by the researchers based on literature review [1, 6, 7, 9, 10, 17–19]. It includes 37 items, the responses being always, often, or never, covering all aspects of palliative care required by terminally ill ESRD geriatric patients during their EOL. According to the holistic concept, older adults have multidimensional EOL needs: physical, emotional, psychological, social, and spiritual needs. In addition to the specific care of hemodialysis therapy including arteriovenous shunt care, care of edema, daily weighting, and frequent measurement of blood pressure. It has internal reliability of 0.85.

#### **Scoring System**

The items discrete scores for each scale (knowledge or practice) were summed together, and then the sum of scores for each dimension and the total score was calculated by summing the scores given for its responses. Also, the mean scores of knowledge and practice were compared before and after the program. All scores were transformed into score % as follows:  $\text{Score \%} = (\text{the observed score} / \text{the maximum score}) \times 100$ . Then, score % was transferred into categories according to the different scales:

- Poor: Score % <50%
- Fair / Satisfactory: Score % 50%<75%
- Good: Score %  $\geq$ 75%

#### **Content Validity**

The tools III and IV were translated into Arabic language by the researchers and reviewed by a committee composed of five experts in the related fields: gerontological nursing, and community health nursing for clarity, relevance, comprehensiveness, and applicability.

#### **Field of Work**

The period of data collection started from the first of January to the end of March 2016, including pilot study, tool validity, and reliability. Each family caregiver of the terminally ill geriatric patient with ESRD who fulfills the inclusion criteria was interviewed on an individual basis to collect necessary data by using tools I, II, III, and IV in the first session. The objective of the first session was to collect the basic data in the hospital setting during the dialysis cycle, then the address and telephone number of the family caregiver were obtained. The researchers listened to the family caregivers carefully without being judgmental; let them freely express their feelings that were either negative or positive feelings, their worries or concerns regarding caregiving process of terminally ill ESRD patients.

The second session was done in the family caregiver's own home to feel relaxed and at ease. The date and time of the next visit, after the arrangement with the family, was determined. The researchers visited each family caregiver twice weekly for a period of five weeks; every visit lasted for an average of one hour. Prior to the visit, the researchers developed guidebook after thorough reviewing of related literature [20–25]. Family caregivers received a copy of this book for preparing them for the role of caregiving of terminally ill geriatric patients with ESRD at home.

The implementation of the program took about 10 sessions. The objective of the second and third sessions was the explanation of the meaning, goals, and the components of the palliative care. The third and fourth sessions emphasized symptoms that the patients may suffered, advices for better cope and practices to manage these symptoms, and the method of prevention. These patients with ESRD usually have heavy symptom burden such as uncontrolled pain, sleep disturbance, fatigue, pruritus, depression, anorexia, vomiting, and dry mouth. The objective of the fifth and sixth sessions was the elaboration of the EOL care, including physical, psychological, and spiritual care. The seventh and eighth sessions included the stages of dying process, signs of imminent death, living wills, advance directives, grief, and bereavement. The ninth session was to refresh the family caregiver's knowledge and to answer their questions. The last and the 10th session was to evaluate of the effect of the program on family caregivers' knowledge and practices.

### **Pilot Study**

A pilot study was done on 10 family caregivers of terminally ill geriatric patient with ESRD selected from the Main University Hospital in Alexandria to assess the tools for their applicability and clarity. Necessary modifications were done, accordingly. The pilot study was carried out in a different setting, in order to have a higher number of the family caregivers in the study setting.

### **Administrative and Ethical Considerations**

Permission to carry out the study was obtained from the responsible authorities which are the Faculty of Nursing Alexandria University and the Head of the Al Moassat Dialysis Unit after explanation of the purpose of the study, the date, and the time of data collection.

Ethical considerations were considered all over the study phases. The informed written consent was obtained from all the study subjects. Privacy and anonymity of the study subjects and confidentiality of the collected data were maintained throughout the study.

### **Statistical Analysis**

Data were analyzed using the Statistical Package for Social Sciences (SPSS Ver. 20, Chicago, IL, USA). Quantitative score data were described using median range. Qualitative data were described using number and percent. Mann–Whitney U-test was used to compare scores between two groups. Kruskal–Wallis test was used to compare scores between more than two groups. Cronbach's alpha test used to assess internal reliability.

Multiple response variables as in questions that have more than one response were analyzed by multiple-response analysis and multiple-response cross-tabulation. In all statistical tests, level of significance of .05 is used, below which the results considered to be statistically significant.

### **RESULT**

The results of the present study is divided into three parts: socio-demographic characteristics and clinical data of the family caregivers and their geriatric patients, effect of a palliative care support program on family caregivers' knowledge and practices, and the correlation between the socio-demographic characteristics of the study subjects, their knowledge and practices regarding palliative care.

Table 1 shows that the mean age of the study subjects is  $49.20 \pm 17.62$ . The age of the main carer ranged from 20 to more than 60 years old, 42.2% of them aged between 40 and less than 60 years. Female caregivers constitute 73.3% of the study subjects. All of them are Muslims. Married caregivers constitute 66.7%. Family caregivers with higher education are 40.0%, 37.8% of them are housewives.

68.9% of the study subjects reported having not enough monthly income, 51.1% of them are daughters/sons. Concerning their health status, 57.8% of them reported having health problems such as arthritis and diabetes mellitus, and 46.7% reported taking some type of medications such as analgesics.

Table 2 illustrates that the mean duration of caregiving of terminally ill geriatric patients is  $5.84 \pm 4.034$ , which is ranged from one to more than 10 years. All study subjects reported that they neither do not have any previous experience of terminally ill patients' caregiving nor receiving any palliative care educational or training program before. 71.1% of them reported that the caregiving process did not affect their lives and activities. 75.5% of family caregivers ask physician help in case of any health problems concerning their patients. 82.2% of them reported that lack of experience is the main worry when caring of ESRD patients. They illustrate that the lack of experience is regarding managing uncontrolled blood pressure, dietary regimen modification, care of arteriovenous shunt, and physical and psychological needs of ESRD patients. 66.7% of them are facing psychological difficulties during caregiving process such as feelings of upset, frustration, helplessness, hopelessness and sadness, followed by physical difficulties such as back and joint pain with 44.4%.

Table 3 demonstrates health profile of terminally ill geriatric patients with ESRD, the duration of being diagnosed with ESRD ranged from 1 to 25 years with a mean of  $9.09 \pm 6.858$ . 46.7% of geriatric patients reported that they are diagnosed since 10 years and more. Concerning the presence of co-morbidities other than ESRD, 62.2%, 53.3%, 51.1%, and 48.9% reported having hypertension, cardiovascular diseases, anemia, and hepatitis C and B, respectively. Regarding taking medications, 57.8%,

55.6%, and 51.1% reported taking cardiovascular medications, vitamins and minerals, and anti-hypertensive, respectively. 77.8% of geriatric patients suffered from physical disability, 35.7% of them reported using a cane as an assistive device, followed by 33.3% of them using wheel chair. Concerning complaining of post-hemodialysis symptoms, 95.6%, 53.3%, and 42.2% of geriatric patients reported suffering from fatigue, hypotension and dizziness, and generalized body ache, respectively. 51.1% of the patients are partially dependent on their caregivers. 66.7% of them reported that difficult transportation is the main difficulty they may encounter to reach hemodialysis session on time, followed by physical disability with 20.0%. 91.1% of geriatric patients reported suffering from sleeping difficulties, which resulted from post-dialysis symptoms such as body ache, noisy environment, and family problems.

Table 4 displays the effect of a palliative care support program, regarding the total knowledge score before the program. The study subjects who have poor knowledge are 73.3% followed by 26.7% of them have fair knowledge. After the implementation of the program, all study subjects have good total knowledge score. As for the practices' subscale, it was found that 95.6%, 75.6%, 95.6%, and 80.0% of the study subjects before the intervention have poor score of physical needs, psychological needs, social needs, and spiritual needs, respectively, and after the study intervention have satisfactory score level for the physical needs by 60.0%, good practice score by 91.1%, 91.1%, and 100.0% for psychological needs, social needs, and spiritual needs, respectively. 75.6% of the study subjects have poor total palliative care practice score and 20.0% of them have satisfactory practice score before the program. After the intervention program, all study subjects have good total score of a palliative care practice.

**Table 1.** Distribution of the family caregivers according to their socio-demographic characteristics and clinical data.

Items	Frequency (n = 45)	Percent %
<b>Age</b>		
• 20 > 40	15	33.3
• 40 > 60	19	42.2
• 60 ≥	11	24.5
<b>Mean ± SD</b>	<b>49.20 ± 17.62</b>	
<b>Sex</b>		
• Female	33	73.3
• Male	12	26.7
<b>Religion</b>		
• Muslim	45	100.0
<b>Marital status</b>		
• Married	30	66.7
• Single	13	28.9
• Divorced	2	4.4
<b>Having children</b>		
• No (single)	13	28.9
• One or two	6	13.3
• 3 or more	26	57.8
<b>Level of education</b>		
• Illiterate or read and write	11	24.3
• Basic education	4	8.8
• Secondary education	12	26.6
• Higher education	18	40.3
<b>Occupation</b>		
• House wife	17	37.7
• Unskilled	11	24.4
• Skilled worker	10	22.2
• Professional	7	15.7
<b>Monthly income</b>		
• Not enough	31	68.9
• Enough	14	31.1
<b>Relation to the geriatric patient</b>		
• Daughter / son	23	51.1
• Spouse	22	48.9
<b>Type of residence</b>		
• Urban	39	86.7
• Rural	6	13.3
<b>Presence health problem</b>		
• Yes	26	57.8
• No	19	42.2
<b>Taking medication</b>		
• No	24	53.3
• Yes	21	46.7

**Table 2.** Distribution of the family caregivers according to their caregiving of terminally ill geriatric patient.

Items	No (n=45)	%
<b>Duration of caregiving</b>		
• 1 > 5	16	35.6
• 5 > 10	17	37.8
• ≥ 10	12	26.6
<b>Mean ± SD</b>	<b>5.84 ± 4.034</b>	
<b>Previous experience of caring with terminally ill patient</b>		
• No	45	100.0
<b>Receiving training / health education regarding palliative care</b>		

• No	45	100.0
<b>Effect of caregiving on their activities of daily living</b>		
• No	32	71.1
• Yes	13	28.9
<b>Seeking medical /health advice</b>		
• Physician	34	75.5
• Nursing staff	7	15.6
• Family members/ relatives	4	8.9
<b>Family caregiver worries regarding providing care to ESRD#</b>		
• Lack of knowledge	2	4.4
• Lack of experience	37	82.2
• Financial problem	3	6.6
• Hemodialysis session	6	13.3
<b>Difficulties facing caregivers during caring with terminally ill geriatric patients#</b>		
• No difficulty	4	8.9
• Physical difficulty	20	44.4
• Psychological difficulty	30	66.7

# More than one answer.

**Table 3.** Distribution of the terminally ill geriatric patients with ESRD according to their health profile.

Items	No (45)	%
<b>Duration of diagnosis with ESRD</b>		
• 1 > 5	9	20.0
• 5 > 10	15	33.3
• ≥ 10	21	46.7
<b>Mean ± SD</b>	9.09 ± 6.858	
<b>Presence of co-morbidities other than ESRD #</b>		
• Hypertension	28	62.2
• Cardiovascular diseases	24	53.3
• Respiratory diseases	4	8.9
• Gastrointestinal diseases	12	26.6
• Anemia	23	51.1
• Endocrine diseases (DM)	17	37.7
• Arthritis	20	44.4
• Hepatitis	22	48.9
• Fall, fracture/osteoporosis	14	31.1
• Benign prostate hyperplasia	6	13.3
<b>Current medications used#</b>		
• No	6	13.3
• Cardiovascular medications	26	57.8
• Antihypertensive	23	51.1
• Respiratory diseases	4	8.9
• Renal diseases	8	17.7
• Gastrointestinal medications	20	44.4
• Vitamins/ minerals	25	55.6
• Antidiabetic	7	15.6
• Analgesics	15	33.3
• Hypnotics	10	22.2
• Hepatitis treatment	4	8.9
<b>Presence of disability</b>		
• No	10	22.2
• Physical disability	35	77.8
<b>Using of an assistive devices</b>		
• No	12	26.6
• Cane	16	35.7

• Walker	2	4.4
• Wheel chair	15	33.3
<b>Post hemodialysis health problems #</b>		
• No	2	4.4
• General body ach	19	42.2
• Fatigue	43	95.6
• Confusion/ disorientation	4	8.9
• Hypotension /dizziness	24	53.3
• Nausea /vomiting	7	15.6
• Dry mouth	2	4.4
• Dry skin	6	13.3
<b>Difficulties to reach the dialysis session on time</b>		
• No	6	13.3
• Difficulty in transportation	30	66.7
• Physical disability	9	20.0
<b>Level of dependency</b>		
• Independent	11	24.4
• Partial independent	23	51.2
• Dependent	11	24.4
<b>Sleeping difficulty</b>		
• No	4	8.9
• Yes	41	91.1

#More than one answer.

**Table 4.** Effect of the study intervention on the knowledge and practice of the family caregivers before and after the program.

Items	Phases of the study interventions			
	Before (Pretest)		After (Posttest)	
	No (45)	%	No (45)	%
<b>Total knowledge score level</b>				
• Poor	33	73.3	0	0.0
• Fair	12	26.7	0	0.0
• Good	0	0.0	45	100.0
<b>Practice score level</b>				
<b>Physical needs</b>				
• Poor	43	95.6	0	0.0
• Satisfactory	2	4.4	27	60.0
• Good	0	0.0	18	40.0
<b>Hemodialysis care</b>				
• Poor	20	44.4	0	0.0
• Satisfactory	21	46.7	7	15.6
• Good	4	8.9	38	84.4
<b>Psychological needs</b>				
• Poor	34	75.6	0	0.0
• Satisfactory	11	24.4	4	8.9
• Good	0	0.0	41	91.1
<b>Social needs</b>				
• Poor	43	95.6	4	8.9
• Satisfactory	0	0.0	0	0.0
• Good	2	4.4	41	91.1
<b>Spiritual needs</b>				
• Poor	36	80.0	0	0.0
• Satisfactory	0	0.0	0	0.0
• Good	9	20.0	45	100.0
<b>Total practice score level</b>				
• Poor	34	75.6	0	0.0
• Satisfactory	9	20.0	0	0.0
• Good	2	4.4	45	100.0

**Table 5.** Effect of the study intervention on the knowledge and practice of the family caregivers before and after the program.

Items	Pre-intervention	Post-intervention	Test value	P
<b>Total knowledge score</b>			Z = 5.859	<.001**
• Median	46.1	88.4		
• (Min–Max)	(30.7–65.3)	(76–96.)		
• Mean ± SD	45.89 ± 8.77	87.77 ± 5.33		
<b>Physical need score</b>			Z = 5.856	<.001**
• Median	33.3	75.0		
• (Min–Max)	(22.9–75.0)	(64.5–87.5)		
• Mean ± SD	36.38 ± 10.49	74.58 ± 5.41		
<b>Hemodialysis care</b>			Z = 5.853	<.001**
• Median	52.9	79.4		
• (Min–Max)	(38.2–82.3)	(70.5–94.1)		
• Mean ± SD	54.90 ± 11.37	81.83 ± 6.31		
<b>Psychological and emotional needs</b>			Z = 5.880	<.001**
• Median	45.0	85.0		
• (Min–Max)	(25.0–70.0)	(75.0–95.0)		
• Mean ± SD	46.22 ± 10.34	84.66 ± 4.57		
<b>Social needs</b>			Z = 6.245	<.001**
• Median	50.0	100.0		
• (Min–Max)	(50.0–100.0)	(50–100)		
• Mean ± SD	52.22 ± 10.42	95.55 ± 14.38		
<b>Spiritual needs</b>			Z = 6.000	<.001**
• Median	50.0	100.0		
• (Min–Max)	(50.0–100.0)	(100–100)		
• Mean ± SD	60.00 ± 20.22	100.00 ± 0.00		
<b>Total practice score</b>			Z = 5.843	<.001**
• Median	47.2	87.5		
• (Min–Max)	(38.8–84.8)	(75.8–94.3)		
• Mean ± SD	49.94 ± 9.41	87.32 ± 3.53		

\*Statistically significant by Wilcoxon Signed-Rank test.

\*\*Statistically significant at  $p < 0$ .**Table 6.** Relation between the socio-demographic characteristics of the family caregivers and their knowledge of palliative care pre and post the intervention program.

Socio-demographic characteristics	Knowledge score (Pre the intervention)			Knowledge score (Post the intervention)		
	Mean (SD)	Test value	P	Mean (SD)	Test value	P
<b>Age (45)</b>						
• 20 > 40 (n = 15)	45.12 ± 6.73	X <sup>2</sup> = 0.652	0.722	87.69 ± 3.90	X <sup>2</sup> = 0.372	0.013*
• 40 > 60 (n = 19)	45.14 ± 7.34			87.24 ± 6.66		
• 60 ≥ (n = 11)	48.25 ± 13.02			88.81 ± 4.69		
<b>Sex</b>						
• Female (n = 33)	44.63 ± 8.96	U = 125.00	0.058	87.76 ± 5.21	U = 188.00	0.810
• Male (n = 12)	49.35 ± 7.48			87.82 ± 5.87		
<b>Marital status</b>						
• Married (n = 30)	46.02 ± 9.86	X <sup>2</sup> = 0.526	0.769	88.58 ± 5.75	X <sup>2</sup> = 4.985	0.083
• Single (n = 13)	46.15 ± 6.66			86.98 ± 3.69		
• Divorced (n = 2)	42.30 ± 0.00			80.76 ± 0.00		
<b>Level of education</b>						
• Low education (illiterate, read & write and basic) (n = 15)	49.36 ± 5.11	X <sup>2</sup> = 2.849	0.583	87.34 ± 4.70	X <sup>2</sup> = 0.137	0.711
• High education (secondary & higher education) (n = 30)	50.23 ± 11.02			87.94 ± 5.68		
<b>Occupation</b>						
• House wife (n = 17)	45.02 ± 8.01	X <sup>2</sup> = 2.807	0.422	87.10 ± 6.22	X <sup>2</sup> = 4.289	0.232
• Unskilled (n = 11)	44.75 ± 7.74			90.20 ± 2.00		
• Skilled worker (n = 10)	48.46 ± 6.58			85.38 ± 5.37		
• Professional (n = 7)	46.15 ± 14.56			89.01 ± 5.63		

<b>Monthly income</b>						
• Not enough (n = 31)	46.52 ± 7.77	X <sup>2</sup> = 1.532	0.216	87.46 ± 5.78	U = 202.00	0.706
• Enough (n = 14)	44.50 ± 10.84			88.46 ± 4.26		
<b>Relation to the geriatric patient</b>						
• Daughter / son (n = 23)	46.15 ± 5.91	U = 244.00	0.837	86.95 ± 5.28	U = 211.50	0.333
• Spouse (n = 22)	45.62 ± 11.15			88.63 ± 5.37		
<b>Having children</b>						
• No (single) (n = 13)	-	X <sup>2</sup> = 0.430	0.837	76.92 ± 0.00	X <sup>2</sup> = 6.648	0.036*
• One or two (n = 6)	46.15 ± 4.44			89.20 ± 5.10		
• 3 or more (n = 26)	45.41 ± 10.49					

X<sup>2</sup>: Chi square value of Kruskal–Wallis test.

U: Mann–Whitney U-test.

\*Statistically significant at p < 0.05.

**Table 7. Relation between socio-demographic characteristics of the family caregivers and their practices of palliative care pre and post the intervention program.**

Socio-demographic characteristics	Practice score (Pre the intervention)			Practice score (Post the intervention)		
	Mean (SD)	Test value	P	Mean (SD)	Test value	p
<b>Age (45)</b>						
• 20 > 40 (n = 15)	47.21 ± 7.11	X <sup>2</sup> = 5.856	0.053	87.41 ± 1.47	X <sup>2</sup> = 8.673	0.013*
• 40 > 60 (n = 19)	50.12 ± 5.17			85.69 ± 4.12		
• 60 ≥ (n = 11)	53.37 ± 15.69			90.02 ± 2.86		
<b>Sex</b>						
• Female (n = 33)	51.63 ± 10.29	U = 138.00	0.123	88.42 ± 2.57	U = 46.00	<0.001**
• Male (n = 12)	45.29 ± 3.72			84.31 ± 4.13		
<b>Marital status</b>						
• Married (n = 30)	51.23 ± 10.25	X <sup>2</sup> = 4.438	0.109	87.28 ± 4.22	X <sup>2</sup> = 0.659	0.719
• Single (n = 13)	47.60 ± 7.60			87.40 ± 1.59		
• Divorced (n = 2)	45.91 ± 0.00			87.46 ± 0.00		
<b>Level of education</b>						
• Low education (illiterate, read & write, and basic) (n = 15)	49.36 ± 5.11	U = 172.00	0.201	87.30 ± 1.24	U = 0.455	0.500
• High education (secondary & higher education) (n = 30)	50.23 ± 11.02			87.94 ± 5.68		
<b>Occupation</b>						
• House wife (n = 17)	50.48 ± 5.35	X <sup>2</sup> = 10.304	0.016*	87.10 ± 2.16	X <sup>2</sup> = 15.43	0.001**
• Unskilled (n = 11)	49.06 ± 7.79			88.42 ± 1.24		
• Skilled worker (n = 10)	45.75 ± 2.29			84.20 ± 4.88		
• Professional (n = 7)	56.00 ± 19.72			90.59 ± 3.10		
<b>Monthly income</b>						
• Not enough (n = 31)	48.87 ± 5.56	U = 1.693	0.193	86.19 ± 3.38	U = 73.00	<0.001**
• Enough (n = 14)	52.32 ± 14.81			89.83 ± 2.43		
<b>Relation to the geriatric patient</b>						
• Daughter / son (n = 23)	47.06 ± 5.70	U = 142.00	0.012*	86.28 ± 3.65	U = 160.00	0.035*
• Spouse (n = 22)	52.96 ± 11.52			88.41 ± 3.12		
<b>Having children</b>						
• One or two (n = 6)	46.58 ± 0.77	X <sup>2</sup> = 2.143	0.342	84.45 ± 0.00	X <sup>2</sup> = 9.010	0.011*
• 3 or more (n = 26)	51.93 ± 10.86			88.38 ± 2.87		

X<sup>2</sup>: Chi-square value of Kruskal–Wallis test.

U: Mann–Whitney U-test.

\*Statistically significant at p < 0.05.

\*\*Statistically significant at p < 0.01.

Table 5 indicates that the mean knowledge score is 45.89 ± 8.77 before the intervention and 87.77 ± 5.33 after the intervention, and the difference is a statistically significant p < .001. As regard

the practices' subscale, the mean score of physical need, hemodialysis care, psychological needs, social needs, and spiritual needs before the study intervention are 36.38 ± 10.49, 54.90 ±

11.37,  $46.22 \pm 10.34$ ,  $52.22 \pm 10.42$ , and  $60.0 \pm 20.22$ , and after the study intervention are  $74.5 \pm 5.41$ ,  $81.83 \pm 6.31$ ,  $84.66 \pm 4.57$ ,  $95.55 \pm 14.38$ , and  $100.0 \pm 0.0$ , respectively. Regarding the total mean score for the practice before the intervention is  $49.94 \pm 9.41$ , and  $87.32 \pm 3.53$  after the intervention, and the difference is a statistically significant  $p < .001$ .

Table 6 shows the relation between the socio-demographic characteristics of the study subjects and their total knowledge score of a palliative care pre and post the intervention program. It was noted that the total knowledge score of the study subjects increases after the program with increasing their age ( $p = 0.013$ ), and the difference is statistically significant. Also, having more children is associated with having good total knowledge score and the difference is statistically significant ( $p = 0.036$ ).

Table 7 illustrates the relation between socio-demographic characteristics of the study subjects and their total practice score of a palliative care before and after the program. It was observed that, increasing the age is associated with better practice score ( $p = 0.013$ ) after the program, and the difference is statistically significant. Also, female caregivers have better total practice score than male caregivers ( $p < .001$ ) after the program, and the difference is statistically significant. Family caregivers with a professional job show better practice score than other jobs before and after the program, and the difference is statistically significant ( $p = 0.016$  and  $p = 0.001$ ), respectively. Families with enough income show better practice than families without enough income; the difference is statistically significant after the program ( $p < .001$ ). It was observed that the spouse caregivers perform better practice than daughters and sons, before and after the program, and the difference is statistically significant ( $p = 0.012$  and  $p = 0.035$ ), respectively. There is a statistically

significant difference between having more children and total score of practice after the program ( $p = 0.011$ ).

## DISCUSSION

As the population ages and people are living longer with increasingly complex conditions called upon to provide care at the EOL. Finding the best ways to support family caregivers should be a health care priority as reported by Kelli I. Stajdubar [26] ESRD geriatric patients and their families are appropriate candidates for palliative care because of their high symptom burden, shortened survival, and significant comorbidity as Holly Jean found [26, 27].

Family caregivers are analogous to the backbone of the EOL care, providing approximately 80% of home patient care [2]. The present study revealed that the main family caregivers are mostly females, married, and housewives. As for the relation between the caregiver and the patient, it was mainly either the daughter or the son. The mean age of all caregivers is  $49.20 \pm 17.62$ . These findings are in agreement with a previous study done in Australia by Peter Hudson which revealed that the majority of the main caregivers are females, and spouses but with a mean age of 59 years [28] The difference in age group between the two studies may be due to the higher life expectancy in the developed countries than developing countries.

Caregiving can be rewarding when caregivers feel that they have improved the quality of life of loved one. Sometimes, however, the burden can result in physical and emotional exhaustion, conflicting emotions, restrictions on the caregiver's own life, and a strain on financial resources [26]. The majority of the family caregivers in the present study reported that the caregiving process did not affect their lives and activities. This finding is consistent with that of Kelli I. Stajdubar in

Australia [26], who reported that despite feelings overburdened, many family caregivers reported that caregiving is a life-enriching experience. One study done in Australia by Peter Hudson reported a contradicting finding as it revealed that family caregiving can have a negative impact on the family's quality of life [29]. From the point of view of the researchers, this finding may be related to the strong family ties in our culture in Egypt as religious obligations.

Family caregivers of geriatric patients with chronic kidney failure have increased burden, as reflected by their high frequency of physical and mental disturbances as revealed by Kwok Ying Chan [30]. The findings of the present study revealed that the majority of the caregivers reported having psychological difficulties as feelings of frustration, helplessness, and hopelessness, followed by the physical difficulties such as back pain. These findings are in agreement with a study done in Japan by Makoto Kobayakawa [31], who reported that psychological distress is problematic for family caregivers of terminally ill geriatric patients. These findings are also consistent with that of Tse Man Wah [32], who revealed that caregivers experienced significantly more psychological distress than physical distress.

Family caregivers can suffer from fatigue, inadequate sleep, and rest. Emotionally, they may have anxiety, depressed mood, and worry about the burden of the uncertainty of future [32]. In the present study, the main family caregivers' worries were the lack of experience in caring with ESRD geriatric patients. As reported by the caregiver, they worry about managing patients' symptoms after dialysis, modification of the diet, and meeting physical and psychological needs of the patients. This finding is consistent with findings of several studies [2, 26, 30, 32],

which revealed that the main family caregivers' worry is the lack of experience and knowledge regarding care of terminally ill patients.

Non-medical obstacles to hemodialysis include lack of transportation, lack of social support, and poor housing. Elderly people have more cardiovascular and overall comorbidity than younger patients, and may experience fall, frailty, and loss of function on dialysis as reported by Berger [33]. The result of the present study showed that the majority of the geriatric patients with ESRD have multiple co-morbidities such as cardiovascular diseases as hypertension, anemia, hepatitis, osteoporosis, recurrent falls, and fractures. The same finding was reported by Kwok Ying Chan in Hong Kong [30]. In the present study, the family caregivers reported that their patients suffered from multiple post-hemodialysis symptoms such as fatigue, hypotension, dizziness, and generalized body ache. The same findings were reported by several studies as reported by Kelli I. Stajdubar et al. [26, 30, 33]. The important obstacle reported by the caregivers of geriatric patients included in the present study is the difficulties in transportation to reach the hospital and attend the hemodialysis session on time. The same result was reported by Berger [33].

The need to support the family caregivers emotionally and practically is expected to grow as healthcare system relies increasingly upon the caregiving labor of family members. With regard the palliative care knowledge and practice of the caregivers before and after the implementation of the study program, the findings of the present study revealed that, knowledge and practice of the caregivers have improved markedly after the program with a statistically significant difference after the implementation than before. There are a plenty of studies that supported these findings as found in the study of

Ching-Ping Hsu in Taiwan et al. [4, 27, 34–37]. These studies showed that caregivers benefit from support groups and educational programs to promote information and caregiving training. Here the researchers felt that, what all required by the caregivers is the provision of knowledge training to improve practice.

There are many factors that may affect family caregivers' knowledge and practice such as age, sex, presence of children, level of education, and the relationship with the geriatric patients [4]. The present study revealed that older age, being female caregiver, have professional job with enough income, and being a spouse are correlated to a higher score level of knowledge and practice. There is a statistically significant difference between age, sex, occupation, monthly income, relation to the geriatric patients, having children of the family caregivers, and their knowledge and practice. There is no significant correlation was found between level of education in this study and the level of knowledge and practice of the study subjects. One study done by Betty J in USA [38] contradicted these findings, which reported that younger caregivers with higher education correlated with higher knowledge and practice score. This contradiction may be related to the small sample size.

The hypothesis of the present study is supported by the study data.

## CONCLUSION

It can be concluded from the findings of the present study that the palliative care support program is found to be effective in improving knowledge and practices of the family caregivers of terminally ill geriatric patients. Thus knowledge and practice of the caregivers have improved after the implementation of the study program than before it with a statistically significant difference.

## RECOMMENDATIONS

Based on the findings of the present study, it can be recommended that:

- Inclusion of the study developed palliative care support program in the plan of care of terminally ill geriatric patients with ESRD to be available for the caregivers by the gerontological and community health nurses after an approval from the responsible authorities in all relevant healthcare settings. This will be done through distributing the developed palliative care support program booklet and hanging of posters on the wall of all healthcare settings where caregivers of geriatric patients with ESRD are present.
- Inclusion of the study developed palliative care support program in both the theory and practical parts of the gerontological and community health nursing courses of the bachelor nursing students.
- Planning and implementation of a training program for all nurses in the relevant healthcare settings to introduce the knowledge and practices included in the palliative care support program to improve the quality of nursing care provided for the patients with ESRD.

## RECOMMENDED FUTURE RESEARCHES

- Development of assessment tools to accurately determine needs of the patient and their family in the EOL care.

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