The Effect of Palliative Care And Training On The Quality of Life of Terminal Stage Cancer Patients And Their Caregivers

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Abstract

Purpose The study aims to determine the effect of palliative care and training provided to caregivers of hospitalized patients with terminal cancer theoretically, practically and visually on their own and patients’ quality of life.

Methods This quasi-experimental study was conducted at a palliative care unit in Turkey between January and June 2019. The study included 35 hospitalized patients with cancer and 35 caregivers. Caregivers were provided with palliative care and training three times a week apart. The data were analyzed using descriptive statistics, Kolmogorov-Smirnov test, Friedman test and iterative analysis of variance.

Results After the palliative care and training, there was an increase in cancer patients’ emotional function sub-scale and global health and decrease in their fatigue and nausea-vomiting symptoms (p<0.05). The mean scores of caregivers from role difficulty, pain, vitality, social function, emotional and mental health sub-scales were high (positively) (p<0.001).

Conclusions Palliative care and training have a positive effect on caregiver burden and recovery in some quality of life sub-scales of both patients and caregivers.

Introduction

Cancer is the second cause of death caused by non-communicable diseases around the world [1]. In 2020, there were roughly 19.3 million new cancer incidences and approximately 10 million deaths [2]. Cancer incidences are estimated to be 30.2 million by 2040 [3]. Cancer, starting from diagnosis to terminal stage, causes serious stress in both patients and caregivers during the treatment and upsets daily life balance. At that period, cancer patients have physical, psychological, social and economic problems [4]. Caregivers of these patients encounter such problems as deterioration in physical and mental health, restriction of time and freedom, job loss, financial difficulties due to changing working hours and problems with caregiver’s spouse, family or social circle during caregiving period [5, 6]. Therefore, cancer patients and their caregivers should be provided with care at all stages of the disease. Palliative care is a multi-disciplinary approach to promote terminal cancer patients’ quality of life (QoL) and prevent disease-driven complications [7, 8]. In palliative care that focuses on QoL, the patient and family should be supported by a holistic approach [9]. The related literature provides evidence that palliative care reduces symptom burden, increases patients’ and caregivers’ QoL and satisfaction, and reduces care burden [9, 10]. However, it is known that primary caregivers do not have sufficient knowledge and skills about caregiving and treatment of terminal cancer patients. This causes emotional, physical and social problems in patients and primary caregivers. Therefore, family members and especially primary caregivers need training and support given by the health care team to provide necessary care [6, 11]. As such, this study aimed to determine the effect of palliative care and training given to women hospitalized with cancer diagnosis on their and patients’ QoL.
Methods

Study Design

This is a quasi-experimental study. The study was conducted between January and June 2019. Quasi-experimental study is suitable for assessing the effect of educational interventions. It is difficult to ensure match-up between the intervention and control group regarding some socio-demographic attributes (age, gender, education level, etc.). In quasi-experimental studies, it is possible to observe changes taking place in the same group over time. Thus, potential impacts of some socio-demographic attributes on outputs of the study can be excluded [12].

Sampling and Settings

The study was conducted with hospitalized female patients of cancer and their primary caregivers in palliative care unit of a hospital in northern region of Turkey. The sample size of the study was calculated using G*Power 3.1 and found to be 19 patients with 95% confidence (1-α), 95.4% test power (1-β), and d=0.92 effect size [13]. The study included 35 patients and 35 primary caregivers. Inclusion criteria for cancer patients were being 18 of age and above, having history of third- or fourth-stage cancer, having no communication problems or any diagnosis of psychiatric disorders and voluntary participation. Inclusion criteria for caregivers were being aged between 18 and 60 years, being literate, primary caregiving to third- or fourth-stage cancer patients, having no communication problems or any diagnosis of psychiatric disorders and voluntary participation.

Intervention and Data Collection

The women hospitalized in palliative care by diagnosis of cancer and their caregivers were informed about training content prior to the intervention. The study included women with cancer and their primary caregivers who agreed to participate. Three days after the first meeting with participants the data collection tools were administered and the first training was provided. The researcher provided the first training to caregivers theoretically, practically and visually. A week after the first training, the data collection tools were repeated and the second training was provided. The researcher provided the second training theoretically and practically with caregivers. The data collection tools were repeated one week after the second training. The third training was provided after the data collection tools. This training evaluated knowledge and skills of caregivers. The training manual, prepared at this stage, was given to caregivers. The data collection tools were repeated one week after the third training. In total, the training was provided three times (Fig. 1). Trainings took at least 45 minutes one week apart. Since 39.3% of the cancer patients under palliative care deceased within three weeks, a week after the third training was the most appropriate time for evaluating efficiency of the training [14]. The data were collected using data collection tools and through face-to-face interview with the participants in all stages of intervention. Each data collection took 40 to 45 minutes.
Training Manual

Palliative care protocol forms basis for individualized care and depends on patients [15]. In this sense, educational planning was made for caregivers considering palliative care protocol. The training manual was prepared with reference to World Health Organization (WHO) [16] and The National Institute for Health and Care Excellence (NICE) [17] palliative care guidelines and NANDA International Nursing Diagnosis book [18] regarding the problems identified in the care of cancer patients in line with the literature [6, 19, 20]. The manual consists of 6 headings, which were general body care, nutrition, physical exercise, psychological support, medication and symptom control. Content and textual sharpness of training manual was evaluated by four experts, including an oncologist and three nurses. The A5 format training manual is colored with 42 pages.

It contains pictures to answer the question “how it is made?” for caregivers. Caregivers were allowed to ask questions frequently. Every heading in the manual, starting with evaluation of caregivers’ and patients’ knowledge and needs, was personalized for both within discussion and training palliative care protocol. Although the manual was standard, the information shared was specific to patients’ and caregivers’ needs. The researcher had a master’s degree in obstetrics and gynecology with 8 years of experience in palliative care service.

Measures

The data collection tools included five sections as indicated below according to the goals and dependent variables.

Questionnaire Form

A questionnaire form was used for the patients and a questionnaire form for caregivers [13, 21, 22]. The questionnaire forms were formed by the researchers with support from the literature. The form included some socio-demographic attributes of patients and caregivers, disease characteristics, and caregivers’ duration of care, and 10 questions in total to determine caregivers’ burden.

EORTC QLQ-C30

This scale, developed by Aaronson et al., consists of 30 items in total [23]. It incorporates five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), and a global health and a QoL scale. The first 28 items are scaled on four-point Likert scale, while the last two items (29, 30) were scored from 1 to 7 points. A higher score from the last two items and functional area showed high QoL, whereas a higher score from symptom control showed low
QoL. Turkish validity and reliability study of the scale was conducted by Beser and Öz and Cronbach’s alpha value was 0.90 [24]. This value was found 0.89 in the current study.

**Short-Form Health Survey (SF-36)**

This scale, developed by Ware and Sherbourne consists of 36 items [25]. The scale consists of eight sub-scales (physical functioning, role physical, energy/fatigue, bodily pain, general health perceptions, social functioning, role emotional and mental health) and two main dimensions (physical and mental). The higher the score obtained from the scale and its subscales is, the higher the quality of life is. Turkish validity and reliability study of the scale was made by Koçyiğit et al. and Cronbach’s alpha was 0.73-0.76 for each sub-scale [26]. This value was found to be 0.89 in the present study.

**Beck Anxiety Inventory (BAI)**

This scale, developed by Beck et al. to measure frequency of anxiety symptoms, consists of 21 items [27]. Each item is scored between 0 and 3. A higher score from the scale shows higher anxiety in individuals. Turkish validity and reliability study of the scale was conducted by Ulusoy et al. and Cronbach’s alpha value was 0.93 [28]. This value was found to be 0.88-0.89 in the current study.

**Caregiver Burden Inventory (CBI)**

This is a 24-item scale developed by Novak and Guest to measure the effect of caregiving on caregivers [29]. The inventory has five sub-scales (time-addiction burden, developmental burden, physical burden, social burden and emotional burden). The scores from the inventory range from 0 to 100. A higher score from the inventory refers to higher burden and lower score shows less burden on caregivers. Turkish validity and reliability study of the scale was conducted by Küçükgüçlü and Cronbach’s alpha value was 0.94 [30]. This value was found to be 0.92 in the current study.

**Data Analysis**

The study's power was calculated using G-Power 3.0 software. The data were analyzed using IBM SPSS 24 software. Descriptive data were shown as number, percentage, mean and standard deviation. Conformity of scale scores to normal distribution was analyzed using Kolmogorov Smirnov test. Whether the normally distributed data differed by evaluations was analyzed using the repeated analysis of variance, and comparison of the data that did not conform to normal distribution was analyzed using the Friedman test. The mean was given as ± standard deviation for normally distributed quantitative data, and the median (min-max) for non-normally distributed data. Based on the results, the confidence interval was 95% and significance level was taken as p<0.05.
Results

Table 1 shows some socio-demographic and disease process characteristics of patients and some socio-demographic and care process characteristics of caregivers. Mean age of the cancer patients was $69.6 \pm 15$, about half of them (48.6%) were married and most were illiterate (57.1%). Most of the patients were diagnosed with cancer at the fourth-stage (68.6%) 7–12 months ago (42.9%) and the cancer type was found to be mostly gastrointestinal system cancer (25.7%). On the other hand, 82.9% of the primary caregivers were female with mean age of $40.06 \pm 12.26$, 42.9% were high-school graduates and 68.6% were married. Of the caregivers, 57.1% have been providing care for less than 12 months.
| Characteristics                                      | Patient n (n (%)) | Caregiver n (n (%)) |
|-----------------------------------------------------|-------------------|---------------------|
| Age (year)                                          | 69.63 ± 14.96     | 40.06 ± 12.26       |
| Gender                                              |                   |                     |
| Male                                                | -                 | 6 (17.1)            |
| Female                                              | 35 (100)          | 29 (82.9)           |
| Marital Status                                      |                   |                     |
| Single                                              | 18 (51.4)         | 11 (31.4)           |
| Married                                             | 17 (48.6)         | 24 (68.6)           |
| Education Status                                    |                   |                     |
| Illiterate                                          | 20 (57.1)         | -                   |
| Primary school                                      | 12 (34.3)         | 12 (34.2)           |
| Secondary school                                    | -                 | 3 (8.6)             |
| High school                                         | -                 | 15 (42.9)           |
| University                                          | 3 (8.6)           | 5 (14.3)            |
| Type of Cancer                                      |                   |                     |
| Gastrointestinal system (Colon. Stomach)            | 9 (25.7)          | -                   |
| Breast and Gynaecology (Endometrium. Cervical)      | 7 (20.0)          | -                   |
| Other (Skin. Brain)                                 | 7 (20.0)          | -                   |
| Pancreas                                            | 6 (17.1)          | -                   |
| Lungs                                               | 3 (8.6)           | -                   |
| Hematological                                       | 3 (8.6)           | -                   |
| Time since diagnoses (in months)                    |                   |                     |
| 0 to 6                                              | 8 (22.9)          | -                   |
| 7 to 12                                             | 15 (42.9)         | -                   |
| >12                                                 | 12 (34.3)         | -                   |
| Diagnosed stage                                     |                   |                     |
| Stage 3                                              | 11 (31.4)         | -                   |
| Stage 4                                              | 24 (68.6)         | -                   |
Table 2 shows mean score comparison of cancer patients from EORTC QLQ-C30 and BAI pre- and post-palliative care and training. After the palliative care and training, there was an increase in patients’ emotional function sub-scale and global health and decrease in their fatigue and nausea-vomiting symptoms (p < 0.005). Whereas patients’ anxiety level was mild pre-training (8–15 points), it turned to be minimum post-training (0–7 points) (p < 0.001).
Table 2
Comparison EORTC QLQ-C30 scale and Beck Anxiety Inventory (BAI) mean scores of female cancer patients from pre- and post-palliative care and training

| Assessments                      | Baseline | First Assessment | Second Assessment | Third Assessment | p         |
|----------------------------------|----------|-----------------|-------------------|-----------------|-----------|
| **EORTC OLQ-C30 Total Score**    | 72.5 ± 13.1 | 73.4 ± 12.9     | 69.7 ± 12.9       | 69 ± 12.9       | 0.050**   |
| **Functional Scales**            |          |                 |                   |                 |           |
| Physical (PF)                    | 46.7 (0–100) | 46.7 (0–100)   | 40 (0–100)        | 33.3 (0–100)    | 0.231*    |
| Role (RF)                        | 33.3 (0–100) | 33.3 (0–100)   | 33.3 (0–100)      | 33.3 (0–100)    | 0.289*    |
| Emotional (EF)                   | 83.3 (50–100)a | 83.3 (50–100)a | 83.3 (50–100)b   | 91.7 (41.7–100)b | < 0.001*  |
| Cognitive (CF)                   | 66.7 (0–100) | 66.7 (0–100)   | 66.7 (33.3–100)   | 83.3 (16.7–100) | 0.912*    |
| Social (SF)                      | 33.3 (0–83.3) | 33.3 (0–83.3) | 33.3 (0–83.3)     | 33.3 (0–83.3)   | 0.067*    |
| Global health status/QOL         | 41.7 (16.7–75)ab | 50 (16.7–75)a  | 50 (25–83.3)b    | 50 (16.7–83.3)ab | 0.002*    |
| **Symptoms/Single Items**        |          |                 |                   |                 |           |
| Fatigue (FA)                     | 55.6 (0–100)ab | 66.7 (22.2–100)a | 44.4 (0–100)ab   | 44.4 (0–100)b   | 0.003*    |
| Nausea (NV)                      | 33.3 (0–100)ab | 33.3 (0–100)a  | 16.7 (0–100)b    | 16.7 (0–100)b   | < 0.001*  |
| Pain (PA)                        | 66.7 (0–100) | 66.7 (16.7–100) | 50 (16.7–100)    | 50 (16.7–100)   | 0.050*    |
| Dyspnoea (DY)                    | 33.3 (0–100) | 33.3 (0–100)   | 33.3 (0–100)     | 33.3 (0–100)    | 0.198*    |
| Insomnia (SL)                    | 33.3 (0–100) | 33.3 (0–100)   | 33.3 (0–100)     | 33.3 (0–100)    | 0.201*    |

*Friedman test. **Repeated analysis of variance. a.b: No significant differences between groups that share the same letter in the same line.

x The higher score, the better the level of functioning. y The higher the score, the worse the symptoms/problems. p < 0.05 indicate significance
| Assessments       | Pre-palliative | Post-palliative | Pre-training | Post-training | p-value |
|-------------------|----------------|-----------------|--------------|---------------|---------|
| Appetite Loss (AP) | 66.7 (0–100)   | 66.7 (0–100)    | 33.3 (0–100) | 33.3 (0–100)  | 0.050*  |
| Constipation (CO)  | 33.3 (0–100)   | 33.3 (0–100)    | 33.3 (0–66.7)| 33.3 (0–100)  | 0.878*  |
| Diarrhoea (DI)     | 0 (0–66.7)     | 0 (0–66.7)      | 0 (0–0)      | 0 (0–33.3)    | 0.050*  |
| Financial (FI)     | 0 (0–100)      | 0 (0–66.7)      | 0 (0–66.7)   | 0 (0–66.7)    | 0.232*  |
| BAI Total Score    | 11.63 ± 8.35a  | 11 ± 7.4a       | 7.86 ± 5.31b | 6.91 ± 4.8b   | < 0.001** |

*Friedman test. **Repeated analysis of variance. a.b: No significant differences between groups that share the same letter in the same line.

The higher score, the better the level of functioning. The higher the score, the worse the symptoms/problems. p < 0.05 indicate significance.

Table 3 shows comparison of SF-36, CBI and BAI mean scores of primary caregivers pre- and post-palliative care and training. The mean scores of caregivers after palliative care and training from role difficulty, pain, vitality, social function, emotional and mental health sub-scales were high (positively) (p < 0.05). Caregiving burden of caregivers was found to be high (32.53) and there was a significant decrease in the developmental and physical burden sub-scale only post-training (p < 0.05). Although BAI mean scores of caregivers diminished post-training, the difference pre- and post-training was not significant (p > 0.05).
Table 3
Comparison of Short-Form Health Survey (SF-36), Caregiver Burden Inventory (CBI) and Beck Anxiety Inventory (BAI) mean scores of primary caregivers pre- and post-palliative care and training

| Measures                  | Baseline | First Assessment | Second Assessment | Third Assessment | p  |
|---------------------------|----------|------------------|-------------------|------------------|----|
| **SF-36**                 |          |                  |                   |                  |    |
| Physical functioning (PF)| 29 (18–75) | 29 (18–30) | 29 (21–30) | 29 (21–30) | 0.050* |
| Role physical (RP)        | 7 (4–25)a | 6 (4–8)a | 8 (4–8)b | 8 (4–8)b | < 0.001* |
| Bodily pain (BP)          | 7 (4–45)a | 8 (4–10)a | 9 (5–10)b | 9 (6–10)b | < 0.001* |
| General health (GH)       | 19.4 (9–75) | 19.4 (9–23.4) | 20.4 (9–23.4) | 20.4 (12–24.4) | 0.057* |
| Vitality (VT)             | 16 (7–65)a | 16 (7–22)a | 18 (7–22)b | 18 (10–22)b | < 0.001* |
| Social functioning (SF)   | 6 (2–87.5)a | 6 (2–9)a | 7 (3–9)b | 7 (4–9)b | < 0.001* |
| Role emotional (RE)       | 5 (3–100)a | 5 (3–6)a | 6 (3–6)ab | 6 (3–6)b | < 0.001* |
| Mental health (MH)        | 24 (16–64)a | 24 (16–29)a | 25 (13–30)b | 25 (17–30)b | < 0.001* |
| **CBI**                   |          |                  |                   |                  |    |
| Time dependency           | 10.83 ± 6.11 | 10.66 ± 6.11 | 10.26 ± 6.15 | 10.31 ± 6.21 | 0.284** |
| Development               | 9.34 ± 4.41a | 9.11 ± 4.57a | 6.63 ± 4.34b | 6.29 ± 4.13b | < 0.001** |
| Physical health           | 8.07 ± 5.83a | 7.82 ± 5.88a | 5.75 ± 4.86b | 5.39 ± 4.48b | < 0.001** |
| Social relationships      | 3 (0–14) | 3 (0–14) | 2 (0–13) | 2 (0–8) | 0.050* |
| Emotional health          | 0 (0–6) | 0 (0–6) | 0 (0–6) | 0 (0–4) | 0.050* |
| CBI Total score           | 32.53 ± 17.12 | 31.68 ± 17.1 | 25.95 ± 16.23 | 24.88 ± 14.77 | 0.050** |
| BAI Total Score           | 5 (0–31) | 3 (0–27) | 2 (0–14) | 2 (0–12) | 0.050* |

*Friedman test. **Repeated analysis of variance. a,b: No significant differences between groups that share the same letter in the same line.
Discussion

The cancer affects negatively the patient’s QoL with secondary problems such as pain, nausea-vomiting, fatigue, insomnia and malnourishment [31]. QoL is deemed an important result criterion in cancer research and treatment [32]. With this study, we aimed to determine the effect of palliative care and training provided to caregivers on the cancer patient’s QoL. After the palliative care and training provided to caregivers in line with the study results, there was an increase in cancer patients’ emotional function sub-scale and global health and decrease in their fatigue and nausea-vomiting symptoms. Kristanti et al. [13] stated that basic skills training provided to caregivers had a positive effect on some sub-scales of cancer patients’ QoL (global health, emotional function, social function, fatigue, pain, dyspnea, insomnia, loss of appetite, constipation and financial difficulties). Belgacem et al. [21] reported that the training program (feeding support, nursing care, care support and management of symptom) aiming to decrease caregivers’ burden positively affected patients’ QoL. This result supported the study by Maltoni et al. [33] who stated that the systematic review of a small number of trials indicated early palliative care interventions to possibly have more beneficial effects on QoL and symptoms intensity among patients with advanced cancer than those provided merely standard cancer care. Also, whereas anxiety of patients was mild prior to palliative care and training in this study, they had minimum anxiety post-training. Hence, recovery in their anxiety levels indicated the efficiency of training. Similarly, Mohabbat-Bahar et al. [34] reported in their experimental study with breast cancer patients that there was a significant difference between mean scores of anxiety pre- and post-training. Cancer patients with anxiety have lower QoL [35]. Therefore, palliative care and training provided to caregivers have a positive effect on patients’ QoL, so positively affect their anxiety levels. In this regard, all health care professionals should provide the appropriate training and care to patients. Precautions should be improved for better QoL and effective management of symptoms.

Long stay of caregivers at hospital during palliative care causes emotional problems such as role change and difficulty adapting to changing roles, anxiety, depression, mourning, distress, burnout, despair, and social isolation and negatively affects their QoL. The studies conducted indicate that general well-being of caregivers deteriorates due to caregiving, caregiving burden is tough and as care burden increases, QoL decreases [5, 6, 36, 37]. Therefore, performing timely interventions is important for caregivers. In this study, our second goal was to determine the effect of palliative care and training provided to caregivers on their QoL. The results showed that there were improvements in the caregivers’ role difficulty, pain, vitality, social function, emotional and mental health at the end of palliative care and training. Also, caregiving burden of caregivers was high in the first evaluation and there was a significant decrease in the developmental and physical burden sub-scale only post-training. Similarly, Uğur and Fadıloğlu [10] reported that palliative care training provided to caregivers of cancer patients decreased their perceived care burden. Lee et al. [38] indicated that an integrated caregiver support program including coping strategies, support, resources and education (CARE) was reported to decrease caregiver burden and to increase self-efficacy of caregivers within 3 months before the death of patients with advanced cancer. The results of similar studies on caregivers’ QoL and care burden also showed that interventions (psychoeducation, skills training, psychosocial intervention, individualized education, palliative care...
counseling, etc.) could promote coping behaviors and self-efficacy (i.e., perceived confidence, readiness, and/or skills to provide care) [39–41] and increase their stress coping skills [42], decrease care burden [11, 21, 43] and make improvements in some sub-skills of QoL [21, 42, 43]. Therefore, the study results show that health care professionals should contribute to increasing QoL of caregivers of cancer patients and decrease their care burden. Nurses should evaluate family members who provide care to terminal stage patients holistically, should support them in the decision-making process, in performing spiritual and cultural practices, in self-care and in adapting to the disease with an empathetic and affectionate approach [44].

**Limitations**

As the study design used a non-randomized design, the strength of the study is limited. Another limitation is that the study does not include psychiatric morbidity related to caregivers and which is deemed a possible factor affecting proliferation of care burden and QoL of caregivers. Furthermore, palliative care and training were evaluated in the hospital environment only since patients’ hospitalization was ongoing. A strength of the study is, however, there was no similar study mentioning the patients and caregivers’ QoL, anxiety and caregiver burden levels of palliative care and training.

**Conclusion**

The results of our interventions were positive; providing palliative care and training to caregivers of cancer patients decreased their burden; and it positively affected QoL of both caregivers and the patients. Care burden of caregivers was found to be high, but it decreased post-training, though not significant. Thus, it can be promoted through palliative care and training to be provided to caregivers. Palliative care and training should be initiated when the patient is diagnosed, and the effectiveness of the training should be evaluated by making home visits to increase the QoL, reduce the burden of caregivers and increase the care quality given to patients.

**Declarations**

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**Data availability** Not applicable.
**Code availability** Not applicable.

**Ethics approval** Official permission (dated 27.02.2018 and numbered 23618724/771) and ethical approval (dated 20.04.2018 and 23618724-000-6899) were obtained to conduct the study. The study complied with Declaration of Helsinki. The researchers informed the participants about the study aim. Informed consent forms were obtained from participating patients and caregivers and their information was kept confidential. To minimize risk, every effort was made.

**Consent to participate** Informed consent was obtained from all participants.

**Consent for publication** Not applicable

**Conflicts of interest** The authors declare no competing interests

**References**

1. World Health Organization. Noncommunicable diseases (2021). Available from: https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases. Accessed 2021 May 16

2. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al (2021) Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA Cancer J Clin 71(3):209–49

3. International Agency for Research on Cancer, World Health Organization Cancer Tomorrow (2020). Available from: https://gco.iarc.fr/tomorrow/en/dataviz/isotype. Accessed 2021 May 16

4. Polat Ü, Atamer B (2020) Care burden and unmet care needs of caregivers of cancer patients receiving palliative care. Gazi Journal of Health Sciences 5(2):38–47

5. Kilic ST, Öz F (2019) Problems and quality of life of family members caring cancer patients’ and interventions. Journal of Hacettepe University Faculty of Nursing 6(3):195-203

6. Yıldız E, Dedeli Ö, Çınar Pakyüz S (2016) Evaluation of care burden and quality of life among family caregivers of patients with cancer. Journal of Education and Research in Nursing 13(3): 216-225. https://doi.org/10.5222/HEAD.2016.216

7. Farahat RH, Abdullah WH, Abd El-Bary N, Abd Elalem MS (2020) Effect of an Educational Palliative Nursing Interventions on Selected Outcomes among Patients Having Advanced Cancer. Menoufia Nursing Journal 5(2):1-12. https://doi.org/10.21608/menj.2020.151529

8. Timur Ö, Gündüz N, Altaş H, Turan H, Karaşahin Ö, Tasar P, et al (2021) Burden, quality of life and coping strategies of palliative care patients’ caregivers. Ege J Med 60:1–9
9. Kocak N, Şenel G, Oğuz G, Karaca Ş, Göksel F (2021) Quality of life and burden in family caregivers of patients with advanced cancer receiving specialized palliative care. Indian J Cancer. https://doi.org/10.4103/ijc.IJC_671_19

10. Uğur Ö, Fadıloğlu ZÇ (2012) The effect of planned education applied to caregivers of cancer patients on caregiver burdens. Cumhuriyet Nurs J 1(2):53–8

11. Wu LF, Lin C, Hung YC, Chang LF, Ho CL, Pan HH (2020) Effectiveness of palliative care consultation service on caregiver burden over time between terminally ill cancer and non-cancer family caregivers. Supportive Care in Cancer 28(12):6045-6055. https://doi.org/10.1007/s00520-020-05449-2

12. White H, Sabarwal S (2014) Quasi-experimental design and methods. Available from: https://www.betterevaluation.org/sites/default/files/Quasi-Experimental_Design_and_Methods_ENG.pdf. Accessed 2021 May 25

13. Kristanti MS, Setiyarini S, Effendy C (2017) Enhancing the quality of life for palliative care cancer patients in Indonesia through family caregivers: a pilot study of basic skills training. BMC Palliat Care 16(4):1–7. https://doi.org/10.1186/s12904-016-0178-4

14. McMillan SC, Weitzner M (1998) Quality of life in cancer patients: Use of a revised hospice index. Cancer Pract 6(5):282-8. https://doi.org/10.1046/j.1523-5394.1998.00023.x.

15. Özçelik H, Fadıloğlu Ç, Karabulut B, Uyar M, Elbi H, Eyigör S et al (2014) Case management based multidisciplinary care protocol in the palliative care of cancer patients. AĞRI 26(2):47–56. https://doi.org/10.5505/agri.2014.93585

16. Com Sàrl I (2007) Palliative Care Knowledge into Action Cancer Control WHO Guide for Effective Programmes. Available from: https://www.who.int/cancer/media/FINAL-PalliativeCareModule.pdf. Accessed 2021 Jun 7

17. National Institute for Clinical Excellence. Improving Supportive and Palliative Care for Adults with Cancer (2019). Available from: https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005. Accessed 2021 Jun 7

18. Heather HT, Kamitsuru S (2017) Nursing Diagnoses Definitions and Classification 2018–2020 Eleventh Edition, Turkey

19. Lambert SD, Harrison JD, Smith E, Bonevski B, Carey M, Lawsin C, et al (2012) The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. BMJ Support Palliat Care 2:224–30. http://dx.doi.org/10.1136/bmjspcare-2012-000226

20. Given B, Sherwood PR, Given CW (2017) What knowledge and skills do caregivers need?. J Soc Work Educ 44(SUPPL. 3):115–23. https://doi.org/10.5175/JSWE.2008.773247703
21. Belgacem B, Auclair C, Fedor MC, Brugnon D, Blanquet M, Tournilhac O et al (2013) A caregiver educational program improves quality of life and burden for cancer patients and their caregivers: A randomised clinical trial. Eur J Oncol Nurs 17(6):870–876. https://doi.org/10.1016/j.ejon.2013.04.006

22. Bahrami M, Farzi S (2014) The effect of a supportive educational program based on COPE model on caring burden and quality of life in family caregivers of women with breast cancer. Iran J Nurs Midwifery Res 19(2):119–126

23. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ et al (1993) The European organization for research and treatment of cancer QLQ-C30: A quality-of-life instrument for use in international clinical trials in oncology. J Natl Cancer Inst 85(5):365–376

24. Beser N, Öz F (2003) Anxiety-depression levels and quality of life of patients with lymphoma who are curing chemotherapy. Cumhuriyet University Nurse J 7(1):47–58

25. Ware JE, Sherbourne CD (1993) The MOS 36-Item Short-Form Health Survey (SF-36). Med Care 31(3):247–263

26. Koçyiğit H, Aydemir Ö, Fisek G, Ölmez N, Memiş A (1999) The validity and reliability of Turkish version of the Short Form 36 (SF-36). Turkish J Drugs Therap 12(2):102–6

27. Beck AT, Epstein N, Brown G, Steer RA (1988) An Inventory for Measuring Clinical Anxiety: Psychometric Properties. J Consult Clin Psychol Psychol Assoc Inc 56(6):893–7

28. Ulusoy M, Sahin NH, Erkmen H (1998) Turkish version of the Beck Anxiety Inventory: Psychometric Properties. J Cogn Psychother An Int Q 12(2):163-172

29. Novak M, Guest C (1989) Application of a multidimensional caregiver burden inventory. Gerontologist 29(6):798–803. https://doi.org/10.1093/geront/29.6.798.

30. Küçükgüçlü Ö, Esen A, Yener G (2009) The Reliability and Validity of The Caregiver Burden Inventory in Turkey. J Neurol Sci 26(1):60–73

31. Lafcı D, Yıldız E, Toru F, Karakaya D (2020) Care burden in cancer patients and its effect on caregivers. Health Care Acad J 7(2):105–13

32. Hinz A, Weis J, Faller H, Brähler E, Härter M, Keller M et al (2018) Quality of life in cancer patients—a comparison of inpatient, outpatient, and rehabilitation settings. Support Care Cancer 26(10):3533–3541. https://doi.org/10.1007/s00520-018-4211-4

33. Maltoni M, Scarpi E, Dall’Agata M, Schiavon S, Biasini C, Codecà C et al (2016) Systematic versus on-demand early palliative care: A randomised clinical trial assessing quality of care and treatment aggressiveness near the end of life. Eur J Cancer 69:110–118. https://doi.org/10.1016/j.ejca.2016.10.004
34. Mohabbat-Bahar S, Maleki-Rizi F, Akbari ME, Moradi-Joo M (2015) Effectiveness of group training based on acceptance and commitment therapy on anxiety and depression of women with breast cancer. Iran J Cancer Prev 8(2):71–76

35. Bužgová R, Jarošová D, Hajnová E (2015) Assessing anxiety and depression with respect to the quality of life in cancer inpatients receiving palliative care. Eur J Oncol Nurs 19(6):667–672. https://doi.org/10.1016/j.ejon.2015.04.006

36. Cengiz Z, Turan M, Olmaz D, Erce Ç (2021) Care burden and quality of life in family caregivers of palliative care patients. J Soc Work End-of-Life Palliat Care 17(1):50–63. https://doi.org/10.1080/15524256.2021.1888844

37. Grant M, Sun V, Fujinami R, Juarez G, Klein L, Ferrell B (2013) Family caregiver burden, skills preparedness, and quality of life in non-small-cell lung cancer. Oncol Nurs Forum 40(4):337–346

38. Lee KC, Yiin JJ, Chao YF (2016) Effect of integrated caregiver support on caregiver burden for people taking care of people with cancer at the end of life: A cohort and quasi-experimental clinical trial. Int J Nurs Stud 56:17–26. https://doi.org/10.1016/j.ijnurstu.2016.01.002

39. Hendrix CC, Bailey DE, Steinhauser KE, Olsen MK, Stechuchak KM, Lowman SG et al (2016) Effects of enhanced caregiver training program on cancer caregiver’s self-efficacy, preparedness, and psychological well-being. Support Care Cancer 24(1):327–336. https://doi.org/10.1007/s00520-015-2797-3

40. Hendrix CC, Landerman R, Abernethy AP (2013) Effects of an individualized caregiver training intervention on self-efficacy of cancer caregivers. West J Nurs Res 35(5):590–610. https://doi.org/10.1177/0193945911420742

41. Thomas Hebdon MC, Coombs LA, Reed P, Crane TE, Badger TA. Self-efficacy in caregivers of adults diagnosed with cancer: An integrative review. European Journal of Oncology Nursing 52: 101933. https://doi.org/10.1016/j.ejon.2021.101933

42. Çetin Ö, Nehir S (2020) Effects of psychoeducation on palliative caregivers’ quality of life and skills to cope with stress. Cukurova Med J 45(3):785–94. https://doi.org/10.17826/cumj.649713

43. Gabriel IO, Mayers PM (2019) Effects of a psychosocial intervention on the quality of life of primary caregivers of women with breast cancer. Eur J Oncol Nurs 38:85–91. https://doi.org/10.1016/j.ejon.2018.12.003

44. Kongsuwan W, Chaipetch O (2013) Thai Buddhists’ experiences caring for family members who died a peaceful death in intensive care. Int J Palliat Nurs 17(7):329–36. https://doi.org/10.12968/ijpn.2011.17.7.329

Figures
Figure 1

Time line and intervention details

**Intervention:** Palliative Care Training  
**Learning methods:** Theoretically, practically and visually  
**Outcome measurement:** -Quality of Life  
- Caregiver Burden  
- Level of anxiety  

**Module contents:**  
1. General body care  
2. Nutrition  
3. Physical exercise  
4. Psychological support  
5. Medication  
6. Symptom control