



# Challenges Experienced by and Quality of Life of Relatives of Cancer Patients Requiring Palliative Care at Home

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## OBJECTIVE

The aim of this descriptive study was to determine challenges experienced by and quality of life of relatives of cancer patients requiring palliative care at home.

## METHODS

This research was conducted with the relatives of patients hospitalized in the palliative care service. Data collection tools used in the study were the “Questionnaire to Assess Challenges of Home Care Providers” and the “Caregiver Quality of Life Index-Cancer Scale” (CQOLC).

## RESULTS

Mean age of the caregivers was 44.4±13.2. Of them, 50% were women. Of the women, 61.7% were housewives. Of all caregivers, 75% had difficulty fulfilling their responsibilities, 53.3% experienced problems in maintaining family relationships, 96.7% did not utilize home care services, and 43% did not receive information about home care. The caregivers also had trouble managing the following issues: pain (80%), nausea/vomiting (70%), defecation (56.7%), and mobility (35%). Mean CQOLC score of the caregivers was 49.7. Mean score on subscales of the CQOLC was 21.58 on the burden subscale, 39.7 on the disruptiveness subscale, 57.7 on the financial concern subscale, and 116.1 on the positive adaptation subscale. Respondents' quality of life was generally low.

## CONCLUSION

Palliative care team should be aware of the needs of caregivers and provide support. Expanding the scope and content of palliative and home healthcare services, improving the quality of these services, and organizing well-educated teams in this branch will better meet the needs of patients and their caregivers and promote their quality of life.

**Keywords:** Caregivers; home care; needs; palliative care; quality of life.

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## Introduction

Palliative care is a multidisciplinary care given to prevent or to relieve the symptoms likely to occur in people with a serious illness and to improve their qual-

ity of life.[1] Palliative care is becoming increasingly common for cancer patients, the second most common cause of deaths both in Turkey and in other countries in the world. In parallel with the increases in the number of these services, the terminal period prolongs and thus

healthcare costs increase, the length of hospital stays decreases and home care services become increasingly important. Due to aforementioned reasons, cancer which requires palliative care affects not only the patient but also his/her family members, and the patient's relatives take more responsibilities to meet the care needs of the patient.[2–4] The daily life of caregivers undertaking responsibility to provide healthcare for a person with a chronic illness is affected, their social and family life is interrupted, their productivity decreases, they may lose their jobs, or their role may change. [5–7] Presence of metastasis, worsening of prognosis, prolongation of the duration of the disease and the patient's stress and anxiety adversely affect the psychological state of caregivers. Although all these unfavorable conditions have no clinical symptoms, they sometimes may bring about physical or psychosomatic problems, depending on the burden of the caregiver. It is known that caregivers experience anxiety, depression, fatigue, role conflict, social isolation and many other difficulties more than do patients during the course of the disease.[8–14] A study[15] reports that, of the caregivers, more than 50% experience negative emotional problems resulting from caregiving and 33% experience negative physical health problems. These results show that it is necessary to assess the quality of life of caregivers. Indeed, studies conducted with different samples have shown that the quality of life of caregivers has decreased.[16,17] Two studies conducted with the caregivers of cancer patients[18,19] demonstrated that the quality of life of caregivers who did not receive support from others and had difficulty fulfilling their responsibilities was low. Several other studies have also demonstrated that the degree of the caregiver's closeness to the patient and some of his/her socio-demographic characteristics such as gender,[18–20] older age,[18,19] low level of education,[18] lack of social security, employment status,[21] poor economic status,[18,19] cancer stage of the patient to whom he/she gives care,[11] provision of healthcare to a male patient,[18] and being the first-degree relative of the patient[19] adversely affect the caregiver's quality of life.[18,19,22]

Patient care includes provision of emotional, physical or financial support such as the coordination of the health care and some of the social services the patient receives, maintenance of routine health care (provision of medication, treatment, observation, etc.), provision of personal care (bathing, feeding, putting on dresses, going to the toilet, cleaning after toilet), transportation, doing the shopping, doing trivial household chores, money management, financial support and sharing

the same house. Therefore, the needs of caregivers who assume responsibility to fulfil all these tasks should be determined and caregivers should be empowered. [23,24] Home care nurses should evaluate the patient and the family together by giving holistic care. Nurses working in a palliative care clinic or providing home care should ensure that the patient leads a quality life by holistically, systematically and timely assessing the symptoms of a cancer patient under treatment, providing individualized nursing care and training the patient and family on symptom control. Interventions to be accomplished in company with multidisciplinary teams will positively contribute to the quality of life of both the patient and the caregiver. To plan the interventions regarding the relatives of cancer patients requiring palliative care, it is important to determine their needs. Although considerable research has been performed with cancer patients,[9,10,16,17,19,22,25] rather less research has been performed on the needs of caregivers of palliative care patients and their quality of life and our search for studies on this issue demonstrated that only one qualitative study was conducted to identify the needs of caregivers.[26] This present study, expected to guide initiatives to be organized and to contribute to the relevant literature, was conducted to identify difficulties experienced by and quality of life of relatives of cancer patients requiring palliative care at home.

## Materials and Methods

This descriptive study was carried out in the palliative care service of a training and research hospital between September 1, 2014 and November 1, 2014. The palliative care service has 8 beds in which the health personnel work on 12-hour shifts (between 8 a.m. and 4 p.m., and between 4 p.m. and 8 a.m.). The study population consisted of inpatients with cancer who received palliative care in the palliative care service and their caregivers. Of them, 60 patients in the 18 and over age group diagnosed with cancer who received inpatient palliative care between September 1, 2014 and November 1, 2014 and their caregivers comprised the study sample. Of the caregivers, those whose patients were not in the terminal period, who had a speaking, hearing or communication problem, who had a psychiatric disorder and/or who did not want to participate in the study were not included in the study.

## Data collection tools used in the study

In the study, the "Questionnaire to Assess Difficulties of Home Care Providers" and the "Caregiver Quality

of Life Index - Cancer Scale - CQOLC” were used to collect data.

**Questionnaire to Assess Challenges of Home Care Providers:** The questionnaire was developed by the two researchers in the light of the relevant literature and similar studies.[2,4,6–10,16] One of the researchers had a four-year medical oncology experience and a 3-year palliative care service experience. The other researcher had an 11-year clinical oncology experience.

After the questionnaire was prepared, opinions of two oncologists, three academicians and three clinical nurse specialists were obtained, and then the items in the questionnaire were revised in accordance with their the suggestions. The questionnaire is made up of two sections including open and closed-ended questions about the patient and the caregiver. While the first part questioned the sociodemographic and disease characteristics of the patient, the second part included 32 items questioning sociodemographic characteristics of the caregivers (age, gender, education, health status and health perception of the caregiver, and the degree of kinship between the caregiver and patient, etc.), length of healthcare provision, home care practices, and difficulties in the provision of home care.

**The Caregiver Quality of Life Index Cancer Scale –CQOLC:** The scale was developed by Weitzner et al., in 1999 to assess physical, emotional, social, and family aspects of the quality of life of caregivers of cancer patients.[27] Yakar and Pınar (2009) conducted the Turkish language equivalence, reliability and validity studies of the scale,[16] and they determined the Cronbach’s Alpha value as 0.88 as in the present study. The scale has 35 items rated on a five-point Likert scale (0=Not at all, 1=A little bit, 2=Somewhat, 3=Quite a bit, 4=Very much). Ten of these items are related to burden, 7 to disruptiveness, 7 to positive adaptation and 3 to financial concern. The remaining 8 items (sleep problems, satisfaction with sexual life, suppression of daily life, mental fatigue, being informed about the disease, protection of the patient, management of the pain of the patient, and the family’s interest in providing care) are assessed independently of the aforementioned four dimensions and contribute to the total score of the scale. While the items “4, 10, 12, 16, 23, 27, 28 and 34” are the non-reverse scored items, the remaining are the reverse-scored items. The overall score of the scale calculated with a special scoring method[16] ranges from 0 to 140. The higher the score obtained from the scale is, the better the quality of life of the caregiver is. Permis-

sion to use the scale in the study was obtained from Yakar through email.

### Data collection process

Prior to data collection, ethical approval was obtained from the Non-interventional Clinical Research Ethics Committee (Date: August 28, 2014, Number: 197), permission from the training and research hospital administration, and written consent from the participating caregivers. The data were collected through face-to-face interviews in a room in the clinic, where the interviews would not be interrupted by the third parties. Each interview lasted 15-25 minutes.

### Statistical analysis

The data were analyzed using the SPSS 22.0 program. Numbers, percentage distribution and mean values were used for the descriptive data. The quantitative data were normally distributed (Kolmogorov-Smirnov > 0.05). The relationship between age and the scores obtained from the CQOLC scale and its subscales was analyzed with the Pearson correlation analysis. The relationship between gender and employment status and the scores obtained from the CQOLC scale and its subscales was analyzed with the t-test. The relationship between education and the scores obtained from the CQOLC scale and its subscales was analyzed with the variance analysis. At the 95% confidence interval, the P value of <0.05 was considered statistically significant.

## Results

### Sociodemographic characteristics of the patients and their caregivers

The mean age of the participating patients was  $56.2 \pm 1.7$  50%. Of the patients, 50% were female, 81.7% were married, 81.7% were primary school graduates, 78.3% were unemployed, 50% had an income equal to their expenses and 48.3% had an income less than their expenses. The cancer types whose incidences ranked the first, second and third were breast (20%), stomach (16.7%) and lung cancer (15%) respectively. The leading reason for admission to the hospital was symptomatic complaints (75%). The mean duration of being diagnosed with cancer was 12 months (min. 1 month, max. 60 months). The mean age of the caregivers was  $44.4 \pm 13.2$ . Of them, 56.7% were between ages of 40 and 60 years, 35% were under the age of 40, 75% were female, 81.7% were married and had children, 76.7% were primary school graduates and 61.3% were unemployed, 50% had an income equal to their expenses, 46.7% were the spouses of the

**Table 1** Distribution of sociodemographic characteristics of the patients and caregivers (n=60)

| Characteristics                         | Patient   |      | Caregivers |      |
|---|-----------|------|------------|------|
|   | n         | %    | n          | %    |
| Age                                     | 56.2 ±1.7 |      | 44.4±13.2  |      |
| Gender                                  |           |      |            |      |
| Female                                  | 30        | 50.0 | 45         | 75.0 |
| Male                                    | 30        | 50.0 | 15         | 25.0 |
| Marital status                          |           |      |            |      |
| Married                                 | 49        | 81.7 | 49         | 81.7 |
| Single                                  | 11        | 18.3 | 11         | 18.3 |
| Education                               |           |      |            |      |
| Illiterate                              | 5         | 8.3  | 3          | 5.0  |
| Primary school                          | 49        | 81.7 | 46         | 76.7 |
| High school                             | 6         | 10.0 | 11         | 18.3 |
| Profession                              |           |      |            |      |
| Self-employed                           | 21        | 35.0 | 10         | 16.7 |
| Worker                                  | 9         | 15.0 | 5          | 8.3  |
| Government officer                      | 4         | 6.7  | 7          | 11.7 |
| Housewife/Unemployed                    | 26        | 43.3 | 38         | 63.3 |
| Income                                  |           |      |            |      |
| Income equal to expenses                | 30        | 50.0 | 30         | 50.0 |
| Income less than expenses               | 29        | 48.3 | 29         | 48.3 |
| Income more than expenses               | 1         | 1.7  | 1          | 1.7  |
| Type of cancer                          |           |      |            |      |
| Breast                                  | 12        | 20.0 | –          | –    |
| Stomach                                 | 10        | 16.7 | –          | –    |
| Lung                                    | 9         | 15.0 | –          | –    |
| Colon                                   | 8         | 13.3 | –          | –    |
| Others                                  | 21        | 35.0 | –          | –    |
| Reason for hospitalization              |           |      |            |      |
| Symptomatic complaints                  | 45        | 75.0 | –          | –    |
| Radiotherapy+<br>symptomatic complaints | 10        | 16.7 | –          | –    |
| Chemotherapy+<br>symptomatic complaints | 5         | 8.3  | –          | –    |
| Total                                   | 60        | 100  |            |      |

patients, 30% were the children of the patients, and 15% were siblings of the patients. The mean duration of the provision of the care was 10 months (min. 2 months, max. 84 months) (Table 1).

### Results on challenges experienced by the caregivers

The challenges faced by the caregivers were as follows: While 81.8% of the employed caregivers could not go to work, and thus they had problems at their work place, 75% of them could not fulfill their responsibilities due to the disease and treatment process. Of the caregivers, 31.7% suffered from stress more due to providing care to a patient with cancer, 13.3% got

**Table 2** Distributions of findings related to the difficulties experienced by patients' relatives providing home care (n=60)

| Data related patients' relatives                     | n  | %    |
|--|----|------|
| Difficulty in working life (n=22)                    |    |      |
| No difficulty  | 4  | 18.2 |
| Not being able to go to work                         | 18 | 81.8 |
| Difficulty in fulfilling responsibilities            |    |      |
| Unable to fulfill responsibilities                   | 45 | 75.0 |
| Able to fulfill responsibilities                     | 15 | 25.0 |
| Difficulties in Relationships with the partner       |    |      |
| Not having difficulty                                | 29 | 48.3 |
| Having difficulty (lack of time, communication etc.) | 31 | 51.8 |
| Difficulty in family relationships                   |    |      |
| Not having difficulty                                | 28 | 46.7 |
| Having difficulty (lack of time, communication etc)  | 32 | 53.3 |
| Difficulty in providing care*                        |    |      |
| Transportation to and from the hospital              | 47 | 78.3 |
| Convincing to have treatment                         | 35 | 58.3 |
| Having the patient take his/her medicine             | 29 | 48.3 |
| Being knowledgeable about home care                  |    |      |
| No   | 26 | 43.3 |
| Yes  | 34 | 56.7 |
| Utilizing homecare services                          |    |      |
| No   | 58 | 96.7 |
| Yes (nutrition; wound care)                          | 2  | 3.4  |
| Difficulties while providing care at home            |    |      |
| Pain management                                      | 48 | 80.0 |
| Nausea/vomiting management                           | 42 | 70.0 |
| Defecation   | 34 | 56.7 |
| Mobilization   | 21 | 35.0 |
| Psychological support                                | 18 | 30.0 |
| Wound care   | 8  | 13.3 |
| Fever management                                     | 7  | 11.7 |
| Communication  | 6  | 10.0 |
| Hygiene  | 5  | 8.3  |
| Total  | 60 | 100  |

\*More than one response.

sick more often, and 51.8% had difficulty in marriage / partnership relationships.

While the 23.3% of the caregivers complained that they could not spare enough time for their spouses, 21% complained about lack of communication between them and their spouses, and 53.3% had difficulties in their relationships with other family members. The greatest challenges the caregivers experienced while they gave care were “transporting the patient to the hospital (78.3%), convincing the patient to have the treatment (58.3%) and feeding the

patient (51.7%)". The leading difficulties the caregivers experienced while they provided home care for their patients were pain management (80%), nausea / vomiting management (70%), defecation (56.7%), mobilization (35%) and psychological support (30%). The least challenging problems they had were hygiene practices (8.3%) and communication (10%) (Table 2). Of the caregivers who participated in the survey, 51.7 stated that there was no other family member to give care for the patient. While 96.7% of the caregivers did not utilize home care services, 98.3% of the rest of the caregivers stated that they utilized home care services but not regularly. Only two of the patients / caregivers utilized home care services.

While 43.3% of the caregivers did not get any information on home care, 56.7% of them did. Of those who received information, 85.2% received information only on medication use, 23.5% only on nutrition and 26.5% both on medication use and on nutrition.

The caregivers stated that while 26.7% of the patients were completely dependent on others while bathing and 23.3% while getting dressed and going to the toilet, 61.7% of them were semi-dependent on others while bathing, 63.3% while getting dressed, 65% while going to the toilet, 71.7% while getting around and 65% while eating and drinking (Table 3).

### Results on the Scores the Caregivers Received from the Caregiver Quality of Life Index - Cancer Scale - CQOLC

The mean score the caregivers received from the CQOLC was  $49.7 \pm 12.7$ . The mean score they received from the subscales of the CQOLC were  $21.58 \pm 17.2$  from the burden subscale,  $39.7 \pm 24.4$  from the disruptiveness subscale,  $57.7 \pm 32.5$  from the financial concern subscale and  $116.1 \pm 12.7$  from the positive adaptation subscale. Their quality of life was generally low (Table 4). Variables such as gender, age and employment status did not affect the mean scores obtained from the CQOLC and its subscales ( $p > 0.05$ ). However, positive adaptation subscale scores of the caregivers who were high school and university graduates were higher ( $F = 4.34$ ,  $p = 0.018$ ) (Table 5).

### Discussion

Cancer is a chronic illness that causes patients and their caregivers to lose control over their lives, affects their social, work, family / marital life adversely, disrupts their health and reduces their quality of life. On the other hand, palliative care services aiming to ensure the

**Table 3** Distribution of Dependency Status of Individuals Receiving Healthcare (n=60)

| Domains            | Independent |      | Semi-dependent |      | Completely-dependent |      |
|--------------------|-------------|------|----------------|------|----------------------|------|
|                    | n           | %*   | n              | %    | n                    | %    |
| Bathing            | 7           | 11.7 | 37             | 61.7 | 16                   | 26.7 |
| Putting on clothes | 8           | 13.3 | 38             | 63.3 | 14                   | 23.3 |
| Defecation         | 7           | 11.7 | 39             | 65.0 | 14                   | 23.3 |
| Mobility           | 6           | 10.0 | 43             | 71.7 | 11                   | 18.3 |
| Nutrition          | 8           | 13.3 | 39             | 65.0 | 13                   | 21.7 |

\*Line percentage.

**Table 4** Distribution of Scores Obtained by the Caregivers from the Caregiver Quality of Life Index - Cancer Scale - CQOLC and its subscales (n=60)

| CQOLC and subscales | X±SD             | Mean  | Min.-Max. |
|---------------------|------------------|-------|-----------|
| Burden              | $21.58 \pm 17.2$ | 19.2  | 0-105     |
| Disruptiveness      | $39.7 \pm 24.4$  | 37.5  | 0-105     |
| Positive adaptation | $116.1 \pm 12.7$ | 120.0 | 85-140    |
| Financial concern   | $57.7 \pm 32.5$  | 52.5  | 0-128     |
| Total CQOLC score   | $49.7 \pm 12.7$  | 47    | 34-94     |

CQOLC: The Caregiver Quality of Life Index Cancer; X: Mean; SD: Standart deviation; Min.: Minimum; Max.: Maximum.

best quality of life and to prevent or relieve symptoms that may occur in cancer patients are becoming increasingly widespread. The results of this present study carried out to determine the difficulties and quality of life of 60 caregivers of cancer patients receiving palliative care at home were discussed in the light of the findings.

In Turkish culture, provision of healthcare is traditionally considered as the responsibility of women, and thus men have difficulty in providing healthcare more than do women.[24] As is seen in the study results, because the majority of caregivers were housewives and unemployed, they were the ones who undertook the responsibility for the provision of healthcare. There are other national[28] and international[6,15,22] studies showing that women are more involved in giving healthcare. In addition, women not only give healthcare, but also continue working, doing housework and fulfilling their childcare responsibilities. The problems associated with all these roles and tasks and the low level of education would make it difficult for women to cope with these problems and increase their risk of developing stress symptoms. Therefore, it becomes essential for health professionals to view female healthcare

**Table 5** Distribution of CQOLC Scores According to Some Socio-demographic Characteristics of the Participants (n=60)

| Characteristics        | n      | Other dimension | Burden     | Disruptiveness | Financial concern | Positive adaptation | Total       |
|------------------------|--------|-----------------|------------|----------------|-------------------|---------------------|-------------|
| Gender                 |        |                 |            |                |                   |                     |             |
| Female                 |        | 6.9±3.7         | 22.2±18.4  | 41.5±24.4      | 58.8±31.3         | 115.8±13.5          | 49.8±12.3   |
| Male                   |        | 7.2±3.1         | 19.6±13.5  | 34.3±24.5      | 54.4±36.8         | 117.0±10.1          | 47.7±12.0   |
| t, p                   |        | -0.25; 0.80     | 0.51; 0.61 | 0.99; 0.32     | 0.45; 0.65        | -0.32; 0.75         | 0.56; 0.57  |
| Education              |        |                 |            |                |                   |                     |             |
| Literate               | 10     | 5.1±1.9         | 14.4±9.8   | 26.5± 14.9     | 46.7±25.8         | 118.0±12.3          | 42.1±5.4    |
| Primary school         | 49     | 7.3±0.3         | 22.5±17.6  | 41.0± 26.2     | 56.3±34.2         | 113.1±12.9          | 49.4±13.4   |
| High school/university | 11     | 7.5±2.2         | 24.8±20.4  | 47.3 ± 21.8    | 72.1±28.5         | 125.0±7.4           | 55.3±9.2    |
| F, p                   |        | 1.77; 0.17      | 1.13; 0.32 | 2.12; 0.12     | 1.72; 0.18        | 4.34; 0.018         | 3.29; 0.05  |
| Employment status      |        |                 |            |                |                   |                     |             |
| Employed               | 18     | 6.9±3.4         | 21.6±13.7  | 35.0±24.8      | 54.4±38.3         | 115.3±11.9          | 47.8±12.3   |
| Unemployed             | 42     | 7.1±3.6         | 21.6±18.7  | 41.8±24.3      | 59.2±29.9         | 116.4±13.2          | 49.9±12.3   |
| t, p                   |        | -0.07; 0.93     | 0.00; 1.00 | -0.98; 0.32    | -0.51; 0.61       | -0.31; 0.75         | -0.59; 0.55 |
| Age                    |        |                 |            |                |                   |                     |             |
| r                      | -0.047 | 0.050           | -0.027     | 0.033          | -0.156            | -0.029              |             |
| p                      | 0.722  | 0.706           | 0.838      | 0.803          | 0.235             | 0.824               |             |

CQOLC: The Caregiver Quality of Life Index Cancer; t: t test, F: One way anova, p: Statistical significance.

providers as a special group of caregivers, to take into account their needs and to support them.

A person's economic status is one of the most important sociodemographic variables affecting his/her quality of life. As a chronic disease, cancer brings significant economic burden both to the patient and to the relatives giving care during diagnosis, treatment and provision of healthcare. This burden can be due indirect expenses (e.g, costs for meals during hospitalization, transport costs, etc.) and direct expenses (diagnosis, treatment and healthcare costs etc.) not paid by their health insurance. Of the relatives of cancer patients, those with low socioeconomic status carry the burden of care more, suffer from negative health conditions more, have problems in accessing treatment and social facilities, and have a financial burden preventing them from coping.[7,18,24,29] That the participating caregivers' income was either equal to or lower than their expenses and that their mean score for the financial concern subscale of the CQOLC was low (57.7) suggest that their quality of life decreased and their healthcare-related burden was high. In addition, the vast majority of employed caregivers (81.8%) had problems going to work (direct costs) and commuting to and from the hospital (indirect costs) (Table 2). Because of all these difficulties, the caregivers were forced to change their living conditions, which negatively affected their quality of life. These results indicate the importance of social services in palliative care services.

Providing healthcare can prevent a caregiver from participating in social life activities (work, recreation, pleasure trips), from maintaining previous relationships and from attending social environments due to his/her recent responsibilities and roles.[24] Thus, establishing a balance between the physical and emotional needs of caregivers will reduce the stress they experience and will promote the quality of life of the patients they look after.[18,24,30] In the present study, approximately half of the caregivers gave care to their spouses for about one year and did not receive any help from any other person. One-third of them suffered from stress more during the care-giving process, lacked time to fulfill responsibilities other than care giving, failed to establish satisfactory communication with his/her spouse or other family members and assumed more responsibilities. In addition, the low scores the caregivers obtained from the burden and disruptiveness subscales of the CQOLC suggest that caregivers had a very low quality of life. Given all these issues, it is extremely important to relieve caregivers with social support systems from time to time. Caregivers who use their social support systems effectively are expected to adapt to their new lives better, to cope with stress easily, to spare more time for themselves and for their relatives and thus to have better quality of life.

Failure to control the symptoms can lead to a feeling of weakness in the life of the patient and his / her family, despair, loss in beliefs and loss of communica-

tion and confidence between the patient and caregivers. Therefore, accurate assessment of a cancer patient's symptoms by his/her caregiver gains importance.[30] In the present study, caregivers had difficulty managing symptoms of pain, nausea, vomiting and constipation at home, almost all of them did not utilize home care services, one-third of them were not knowledgeable about these services, and only one-third of them were informed about medication use. At this point, it is extremely important for palliative care teams to prepare and implement a well-organized training plan that approaches the management of the cancer patient's symptoms holistically, to evaluate the outcomes of the training plan, and to inform caregivers. The patient should be supported on symptom management to be implemented at discharge and at home. The results of the present study[12,31] show that training given on symptom management was effective.

Home healthcare services given by a professional team will reduce the frequency of hospital admissions and improve the quality of life of patients and caregivers, and meet health care expectations of patients and caregivers.[4]

Studies[32,33] on patients receiving home care services have shown that cancer patients are more dependent on someone else's care when performing self-care activities than are other patient groups. In the present study, the patients were semi-dependent on others in performing many activities of daily living, and the issues that were most difficult in the provision of healthcare were related to both medical services and social service applications including instrumental activities of daily living. These findings are important results that increase caregivers' burden and adversely affect their quality of life and highlight the importance of providing medical and social services together in home care services. The analysis of the CQOLC scale scores suggests that the quality of life of the caregivers who participated in the present study in all the subscales was low. This result correlates with the results of two other studies which investigated the quality of life of caregivers of cancer patients.[18,20] Positive adaptation subscale-related quality of life of caregivers with higher levels of education was higher, which suggests that individuals with higher levels of education might have better coping capacities. However, that the participating caregivers' other socio-demographic characteristics did not affect their quality of life scale scores was thought to be due to the small size of the study sample. On the other hand, it has been reported that some socio-demographic characteristics of the caregiver and degree of close-

ness to the caregiver have an impact on their quality of life.[18,19,21,22] It is suggested to perform studies with larger samples to reveal these relationships better.

The present study has various limitations. Firstly, since the palliative care services have just started to be installed in hospitals, their bed capacities are still small. Therefore, the size of the study sample was not at a desired level. Secondly, since the other studies on caregivers' needs and quality of life were conducted in cancer patient clinics without palliative care services, the findings of the present study were compared with the results of the mentioned studies.

### Conclusion

The results of this present study conducted with caregivers of palliative care patients revealed that the caregivers were not knowledgeable enough about home care, and thus they had difficulties in maintaining family relationships, fulfilling their responsibilities, managing the symptoms of patients and they had low level of quality of life in all domains except for the positive adaptation domain. In this respect, it seems inevitable to train caregivers on home care, symptom management, disease process and health services available, to provide counseling, and to support family members by health care team, relatives and friends. On the other hand, expanding the scope and content of palliative care and home care services with experienced teams knowledgeable about this patient group not only will meet the expectations of patients / caregivers but also will contribute to the enhancement of the quality of life of these people.

### Disclosure Statement

The authors declare no conflicts of interest.

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