Home care practices of cancer caregivers and the effect of perceived social support on care burden

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Received: 4 October 2021 / Accepted: 27 June 2022 / Published online: 20 July 2022
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Abstract

Introduction Caregivers have to manage tasks at home such as providing management of the patient’s follow-up. Social support is known to have protective effects, especially for caregivers for cancer patients. The aim of this study is to examine the effect of home care practices and perceived social support level of caregivers of cancer patients on the burden of care.

Methods A descriptive and cross-sectional study. A total of 222 caregivers were included in the study. In this study, Caregiver and Patient Identification Form, Caregiver’s Home Care Practices Questionnaire Form, Zarit Caregiver Burden Scale, Multidimensional Scale of Perceived Social Support, and Karnofsky Performance Scales were used.

Results Of the caregivers included in the study, it was found that 47.3% were in the 40–61 age group, and 64.4% were women. The total score of caregivers from MSPSS was 61.29 ± 17.27, the total score they received from the Home Care Practices Questionnaire was 28.88 ± 7.72, and the total score they got from the ZBI was 29.11 ± 14.58. It was found that there was a weak and negative correlation between the perceived social support total scores and caregiver burden scores of caregivers (p < .01). In particular, in the regression analysis, a significant correlation was found between the total score of home care practices and personal sub-dimension scores (r: .91, p < .001, tolerance value: .158, VIF: 6.311).

Conclusions It has been determined that the increase in home care practices of caregivers of cancer patients and the low level of perceived social support increase the burden of care.

Keywords Caregiver · Caregiver burden · Social support · Home care practices

Introduction

Cancer, which is one of the major health problems today, is a significant cause of morbidity and mortality worldwide [1]. According to the data provided by GLOBOCAN in 2020, the total number of new cancer cases in the world was determined to be 19.292 million and 9.9 million cancer-related deaths were reported. The total incidence of cancer in Turkey is 231.5 per a hundred thousand population and 233.834 new cases of cancer were diagnosed [2]. Due to the great advances in cancer treatment, outpatient treatment has acquired more significance. This shortens the length of hospital stay and causes family members to take over the management of their patients at home and take on increased care responsibilities [3–7].

Caregiver roles and burden of care

Caregivers have to manage chores at home, such as providing follow-up and management of the patient’s symptoms for an average of 8 h per day, and helping with household and children’s chores. Primary responsibilities for the caregiver include the management of the patient’s functional competence (bathing, eating, dressing…) and the management of symptoms related to cancer treatment (pain, fatigue, nausea, vomiting, mucositis…) [8–11]. As the patient’s dependency level increases, the need for help increases. The care given by the caregiver in the care of the cancer patient, the management of the symptoms related to the disease, emotional, material, and moral support, helping the patient’s personal care when necessary when the patient cannot fulfill his/her...
own needs, caring for the medical instruments used for the patient, administering the medication, making decisions on his behalf when necessary, and all of which involve taking responsibility [5, 6, 9]. In the literature, the concept of burden is “depending on the care undertaken by the caregiver”. It emerges in itself, and it is widely reviewed in health, economic problems, social problems, the departure of family relatives, and the course of control. It is reported that the care burden is high regarding caregivers who are not adequately prepared for the management of home care, who have to deal with increasingly complex conditions of patient care, and who lack adequate support while giving care [5–7].

**Caregiver and social support**

In general, social support is defined as the help provided by the individuals around the individual who is under stress or in a difficult situation. The basis of the concept of social support is the assumption that the individual has needs such as being trusted, loved, respected, valued, taken care of, taking responsibility, and belonging to a group. By meeting such needs, the physical and psychological health of the individual will be directly affected and considered to have a positive impact. Although perceived social support does not remove the person’s stressors, it reduces their anxiety levels, and makes them more optimistic, able to control themselves more, and try new ways to cope with problems [3]. Although social supports do not eliminate stressors, they reduce the anxiety levels of individuals and enable them to become more optimistic and more self-controlled, and try new ways of coping with problems [8, 9]. Due to insufficient social support, the physical, social, and mental status of individuals is adversely affected. In this process, caregivers may experience problems such as loneliness, social isolation, and deterioration in interpersonal relationships because of staying away from family, friends, or social activities. They may have difficulty coping with daily stressors and their general quality of life may deteriorate [7, 12, 13]. For this reason, caregivers not only need the support of their families and friends, and feel that they are not left alone, but also receive help with finance, information, education, and social and emotional support [9].

**Social support and caregiver burden**

Social support is known to have protective effects, especially for family members and caregivers for cancer patients [10]. In addition to the caregiver’s burden of care, the social support system is also important in increasing the quality of life of the patient and his family. In this context, the caregiver’s burden of care and the level of social support greatly affect the patient care process. In Turkish society, the needs of individuals to receive safe care at home and their expectations for personalized care are increasing the importance of home care. Home care of cancer patients is also affected by this process. The aim of this study is to examine the effect of home care practices and perceived social support of cancer caregivers on care burden.

**Methods**

**Study design**

This is a descriptive and cross-sectional study. This study was carried out in the Chemotherapy Day Treatment Unit of Dokuz Eylul University Research and Application Hospital, located in the western part of Turkey, in the province of Izmir, between September 2017 and May 2018.

**Participants**

In the study, the sample calculation method of unknown universe was used to determine the sample, and the caregivers of 222 patients who came to the unit for treatment were included. Since there is no clear data on the number of individuals on the relevant subject in our study, the sample method of unknown universe was used. A total of 248 caregivers who met the criteria were included in the study, but 26 did not want to continue. Data were collected in a single session by face-to-face interview method with caregivers. Literature support was received in determining the selection criteria in the study [14, 15]. The research sample is 18 years of age and older, who speaks Turkish, who cares for a patient with an oncological or hematological malignancy, who has lived in the same house with the patient for at least 3 months, who primarily undertakes care responsibilities, who has good cognitive functions, who can communicate comfortably, and who caregivers who were willing to participate in the study were recruited. As the exclusion criteria, the caregivers of the patient with a Karnofsky performance value of 20% or less and the caregivers who were not the primary caregivers of the patient and did not want to participate in the study were excluded from the study. Literature support was received in determining the exclusion criteria in the study [9].

**Data collection tools**

Five data collection tools were used to collect the data of the study. Patient and Caregiver Identification Form was prepared according to the literature review [15–17]. The form consists of questions aiming to identify the sociodemographic and health status of the patients and caregivers.
Caregiver’s Home Care Practices Questionnaire was prepared by the researchers with the support of the literature [15, 16, 18]. It consists of three parts: medical, non-medical, and personal care of the patient. A Likert-type assessment method was used for the evaluation of the items in the questionnaire (0 No, 1 Sometimes, and 2 Yes). Likert scale score options used in evaluation are not mutually exclusive. The higher scores obtained from the survey indicate a higher number of home care practices given to the patient while the lower scores indicate a low number of care-oriented practices. In order to determine the scope validity, expert opinions were obtained from 9 people including 5 faculty members, 2 specialist doctors, and 2 clinically responsible nurses before using the form in the study. After the feedback, the form was finalized. When the scope validity index of the questionnaire was examined, Cronbach’s alpha value was found to be 0.90 for Medical Care Management sub-dimension, 0.83 for Non-Medical Care Management sub-dimension, and 0.98 for Provision of Patient Personal Care sub-dimension. Before the study was started, the questionnaire, which obtained good validity scores, was administered to 3 caregivers to determine its usability. Three caregivers were excluded from the study.

Zarit Caregiver Burden Scale (ZBI) [18] was developed by Reever and Bach-Peterson in 1980. ZBI is for measuring the caregiver’s perceived burden of providing family care. The 22 items are assessed on a 5-point Likert scale, ranging from 0 = “never” to 4 = “nearly always”. Item scores are added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. The questions focus on major areas such as caregiver’s health, psychological well-being, finances, social life, and the relationship between the caregiver and the patient. The test–retest reliability of the Caregiver Burden Scale was found to be very reliable with a coefficient of 0.71–0.60. The validity and reliability of the Turkish version was conducted by İnci. The Cronbach’s alpha value of the scale was found to be 0.95 which was highly reliable [19].

The Multidimensional Scale of Perceived Social Support [20] is a 12-item scale, rated on a 7-point Likert scale, ranging from (1) very strongly disagree to (7) very strongly agree. The scale has three sub-dimensions relating to the source of the social support, namely family, friend, and significant other, each consisting of 4 items. In the scale, items 3, 4, 8, and 11 measure family support; items 6, 7, 9, and 12 measure friend support and items 1, 2, 5, and 10 measure the support from the significant other. The lowest score that can be obtained from the sub-dimensions is 4 while the highest is 28. The lowest score that can be obtained from the total scale is 12 while the highest is 84. The higher the level of social support, Zimet and his colleagues reported a Cronbach alpha level of 0.88 for the scale. They also checked the test–retest reliability of the scale and reported this as 0.85 [20]. Eker et al. studied the factor structure of the MSPSS and confirmed the three-factor solution through an exploratory factor analysis model. The internal consistency coefficient varies between 0.80 and 0.95. Revised by Eker et al. in 2001, it was found to be 0.80–0.95 [21].

Karnofsky Performance Status Scale, which was defined by Dr. Joseph H. Burchenal and Dr. David A. Karnofsky in 1949, is used to evaluate the general well-being of cancer patients in oncology and other fields [22]. It was used to evaluate the performance status of patients cared for by caregivers. The scale is evaluated between 0 and 100 points. A total of 100 points indicate that the patient has no complaints, 40 points require special help and care, and 0 points indicate death.

Collecting research data

The data of the study were collected by face-to-face interviews conducted with the caregivers of cancer patients receiving treatment in the Chemotherapy Day Treatment Unit of Dokuz Eylül University Research and Application Hospital. The data were filled out in the nurse rest room while the patient was receiving chemotherapy in the treatment unit, after written and verbal consent was obtained from the caregivers who met the selection criteria. Data collection took approximately 20 min.

Data analysis

In the evaluation of the data, number, percentage, mean, and standard deviation were used in descriptive statistics. One-way analysis of variance (forward analysis Tukey HSD), t test, and Kruskal Wallis (advanced analysis Mann Whitney U test with Bonferroni correction and Tukey HSD) were used to compare the mean ZBYS score of the cancer caregivers according to the descriptive characteristics. The relationship between the MSPSS scores of the caregivers of cancer patients, the KPS and Home Care Practices Questionnaire Scores of the patients they care for, and ZBYS scores were evaluated with Pearson correlation analysis. The effect of independent variables on the caregiver burden score of caregivers was evaluated with multiple regression (backward method) analysis. The significance level was accepted as \( p < 0.05 \). Table 5 shows the variables that were found to affect the burden of caregivers.

Results

Of the caregivers included in the study \( (n: 222) \), it was found that 47.3% were in the 40–61 age group, 64.4% were women, 73% were married, 37.8% were graduates of higher education, 31.5% were homemakers, 81.08% did not have a
job (homemakers, free, retired), 73.9% had moderate economic status, and 86.5% had social security. It was found that 69.8% of caregivers have a nuclear family type consisting of mother, father, and children, 72.5% had children, and 60.4% were not directly responsible for child care. It was found that 77.9% of the caregivers did not have any chronic diseases, 40.1% cared for their spouses, 33.8% provided care exceeding 19 h per day, 55% cared for their patients for 3–10 months, 60.4% had patients with metastasis, and 23% of the patients had a performance status of 80%.

It was determined that the caregivers conducted the follow-up of their patients’ medical problems, arranged their nutrition, medication, and appointments, helped with the household chores (shopping, childcare, payment of bills), gave their patients emotional support, helped with their exercises, and provided massage. However, it was found that the patients in the sample group were able to perform their own personal care easily because of their high performance status (Table 1).

When the care practices given by the caregivers to their patients at home were examined, it was determined that 81.5% of them followed the medical problems of their patients, 90.1% of them followed the drugs and medical equipment prescribed for their patients, and 76.1% of them followed the nutritional status of their patients. In the non-medical care of the patient, it was determined that 73.4% of them took care of the house (cleaning, repair…), 39.2% were interested in the care of children, and 93.7% followed the patient’s work related to the hospital. When the caregivers’ actions in terms of individual care of the patient were examined, it was found that 41.9% helped the patient to take a bath, 89.6% supported the patient emotionally, and 55.4% helped the patient to do his exercises (Table 2).

While the total score of caregivers from MSPSS was 61.29 ± 17.27, the total score they got from the Home Care Practices Questionnaire was 28.88 ± 7.72, and the total score they got from the ZBI was 29.11 ± 14.58. When the sub-dimensions of the MSPSS were examined, it was 23.05 ± 5.96 for the family dimension, and for the sub-dimensions of the Home Care Practices Questionnaire, the medical care management dimension was 9.00 ± 2.65 points and the individual care dimension sub-dimension 10.41 ± 5.95 points. On the Zarit care burden scale, caregivers were found to have a mild care burden of 51.4 (Table 3).

As seen in Table 4, it was found that there was a weak and negative correlation between the perceived social support total scores and caregiver burden scores of caregivers ($p < 0.05$). A weak and significant negative relationship was found between friend sub-dimension scores and caregiver burden ($p < 0.01$).

A statistically significant positive but weak correlation was found between Karnofsky performance status scores and caregiver burden scores ($p < 0.01$). As the performance scores of the patients decrease, caregivers’ burden scores
### Table 2  Caregiver’s home care practices

| Home care practices                                      | Yes | Sometimes | No |
|----------------------------------------------------------|-----|-----------|----|
| **Medical care management**                              |     |           |    |
| Follow-up of medical problems                            | 181 | 81.5      | 22 | 9.9 |
| Follow-up of medication                                  | 197 | 88.7      | 16 | 7.2 |
| Arranging appointments                                   | 204 | 91.9      | 8  | 3.6 |
| Provision of prescribed drugs and medical equipment      | 200 | 90.1      | 15 | 6.8 |
| Preparation of special diet requirements                 | 169 | 76.1      | 24 | 10.8|
| **Non-medical care management**                          |     |           |    |
| Managing household chores during the care process (cleaning, repair) | 163 | 73.4      | 38 | 17.1|
| Helping with duties related with children during the care process (transportation to school, parent meetings, etc.) | 87  | 39.2      | 16 | 7.2 |
| Doing necessary shopping (clothing, nutrition, special requirements, etc.) | 186 | 83.8      | 27 | 12.2|
| Taking responsibility in the transportation of the patient to hospital | 208 | 93.7      | 9  | 4.1 |
| Paying the bills of the patient (electricity, water, telephone, custom invoices, house rents, etc.) | 136 | 61.3      | 23 | 10.4|
| Having another job during the care process               | 67  | 30.2      | 12 | 5.4 |
| Financial impact on the care process (loss of job, decrease in job continuity, travel or accommodation fees) | 131 | 59.0      | 23 | 10.4|
| **Provision of patient personal care**                   |     |           |    |
| Oral care                                                | 89  | 40.1      | 38 | 17.1|
| Assisting with body care (bathing)                       |     |           |    |
| Foot care                                                | 93  | 41.9      | 46 | 20.7|
| Maintenance of urinary catheter                          | 36  | 16.2      | 10 | 4.5 |
| Maintenance of the feeding tube (feeding, PEG)           | 30  | 13.5      | 4  | 1.9 |
| Supporting the patient emotionally                       | 199 | 89.6      | 8  | 3.7 |
| Performing tube feeding (PEG)                            | 23  | 10.4      | 2  | 0.9 |
| Maintenance of colostomy, ileostomy, or urostomy         | 24  | 10.8      | 5  | 2.3 |
| Maintenance of tracheostomy                              | 18  | 8.1       | 4  | 1.8 |
| Assisting the patient while walking or with in-bed exercises | 123 | 55.4      | 44 | 19.8|
| Wound or catheter dressing                              | 87  | 39.2      | 17 | 7.7 |
| Injection (insulin, blood thinners, blood-forming drugs, etc.) | 114 | 51.4      | 43 | 19.4|

### Table 3  Caregivers’ descriptive statistics of the Multidimensional Scale of Perceived Social Support (n: 222)

| Scale and sub-dimensions                          | Lowest-highest | $x \pm SD$ |
|---------------------------------------------------|-----------------|------------|
| **Multidimensional Scale of Perceived Social Support (MSPSS – total)** | 14–84           | 61.29 ± 17.27 |
| **MSPSS sub-dimensions**                          |                 |            |
| Family                                            | 4–28            | 23.05 ± 5.96 |
| Friend                                            | 4–28            | 20.25 ± 7.10 |
| Significant other                                 | 4–28            | 18.00 ± 7.77 |
| **Caregiver’s Home Care Practices Questionnaire (total)** | 10–50           | 28.88 ± 7.72 |
| **Care sub-dimensions**                           |                 |            |
| Medical care management                           | 4–10            | 9.00 ± 1.60 |
| Non-medical care management                       | 0–14            | 9.48 ± 2.65 |
| Provision of patient personal care                | 0–26            | 10.41 ± 5.95 |
| **Zarit Caregiver Burden Scale total scores**     | 0–88            | 29.11 ± 14.58 |
| **Classification of care burden**                 |                 |            |
| Little or no burden                               | (0–20 points)   | 67         | 30.2 |
| Mild to moderate burden                           | (21–40 points)  | 114        | 51.4 |
| Moderate to severe burden                         | (41–60 points)  | 36         | 16.2 |
| Severe burden                                     | (61–88 points)  | 5          | 2.3  |
increase. When the relationships between Home Care Practices Questionnaire Scores and ZBI scores were examined, a moderately positive, significant correlation was found ($p < 0.001$). It was found that there was no significant relationship between the medical and non-medical care management sub-dimension scores and caregiver burden scores ($p > 0.05$). However, a moderately positive and significant correlation was found between the provision of patient personal care sub-dimension scores and caregiver burden scores ($p < 0.001$). It was found that as the total score of home care practices and the provision of patient personal care sub-dimension scores increased, caregiver burden scores also increased (Table 4).

A significant correlation was found between the diagnostic duration and the duration of care provision ($r: 0.93$, $p < 0.001$, tolerance value: 0.128, VIF: 7.811) and the MSPSS total scores and the friend sub-dimension scores ($r: 0.83$, $p < .001$, tolerance value: 0.274, VIF: 3.649). In addition, a significant correlation was found between daily care practices total score and personal care sub-dimension scores ($r: 0.91$, $p < 0.001$, tolerance value: 0.158, VIF: 6.311). In the study, the effect of the variable of the caregiver having to provide care for persons other than cancer patients on the caregiver burden was found to be significant ($p: 0.05$ to $0.10$, $0.05 < p < 0.10$). They will be set to schedule maintenance this model has been taken. The five independent variables explain the variance in caregiver burden score by 20% (Table 5). While the 1-point increase in the personal care sub-dimension scores of the Home Care Practices Questionnaire increases the caregiver burden scores by 0.77 points; 1-point increase in the friend sub-dimension scores of the MSPSS decreases the caregiver burden scores by $-0.31$ points. The caregiver burden score of the caregivers with the broken family type was found to be 4.46 points higher than the caregivers with the extended and nuclear family type. The burden score of the caregivers who were solely responsible for the care of their patients was 4.07 points higher than the...
caregivers who received support; the scores of the caregivers of patients with metastases were found to be 4.07 points higher than those of caregivers of patients without metastasis. The burden score of those who care for someone else besides their patient was 3.63 points higher than those who care only for their patients (Table 5).

Discussion

It is important to reduce the difficulties that caregivers may experience at home and to prepare for home care in clinics. This will also reduce the burden of the caregiver. The involvement of the social support network in care is important. For this reason, our study was conducted to examine the effect of home care practices and perceived social support level of caregivers of cancer patients on the burden of care.

Caregiver’s descriptive statistics

In this study, it was found that 64.4% were women. In the Turkish family structure survey of the Ministry of Family and Social Policies, it is stated that most of the housework (88%) is done by women in households. In Turkey-wide results, it is emphasized that care work is undertaken by spouses, mothers, and female partners, respectively, in homes with sick individuals in need of care [5, 23]. In a study conducted by Altun et al., it was found that 78% of caregivers were women and 34% cared for their spouses. In this aspect, our study is similar to the literature [7]. In the literature, it is emphasized that caregiving is influenced by cultural structures and that caregiving is a responsibility traditionally fulfilled by female members of the family [24–26]. In Türkoğlu and Kılıç’s study examining the quality of life and care burden of caregivers of cancer patients, it was determined that the demographic characteristics of the caregivers and the burden of care had an effect on the quality of life of the caregivers [26]. In our study, it was found that caregivers had a high level of education. In the literature, there are studies that are supportive of our findings [5, 9, 14, 15].

In our study, Table 1 shows the whole of the work carried out by the caregivers in this process while giving care to their patients. In the literature, it is stated that caregivers are old or young, have low education level, have low social support or live alone, have difficulty in caring for patients with advanced cancer, have complex medical treatments, and have difficulties in the care of patients with intensive care. These are variables that negatively affect the burden of caregivers [27, 28]. In this respect, our study is similar to other studies [9, 25, 29].

Perceived social support level of the caregivers

In the literature, there are reasons such as loss of participation in social activities of the caregiver, losses due to emotional changes, inability to fulfill his social role, lack of social support, losses experienced in the financial field, and losses related to the patient’s former state that negatively affect the quality of life of the caregiver [27, 28, 30]. In our study, it was determined that the perceived social support level of the caregivers was moderately sufficient (Table 3). Moderate level of social support includes finding a balance between the caregiver’s needs for caregiving and social support resources. In the study of Babaoğlu and Öz in which they examined the problems experienced by spouses who care for cancer patients, it was determined that spouses who care for cancer suffer from depressive affective disorder and decrease in their social interactions. When the sub-dimensions were examined, it was determined that the caregivers perceived the support received from family more than the support from friends or significant others. It is thought to be stemming from the fact that spouses, children, and other family members support each other in case of an illness according to the traditional Turkish family structure [11]. This finding is in line with those similar [11, 13, 27].

Burden scores of the caregivers

In our study, it was determined that caregivers had a light burden of care (Table 5). In the literature, it has been determined that caregivers of patients with high performance status have better caregiver scores than caregivers of patients with poor performance status [9]. It is emphasized that especially the increased caregiver burden causes depressive disorders in caregivers. In this context, it is stated that social support acts as a buffer against diseases by reducing or balancing the damages caused by life stress [12]. In the study, it was found that the burden scores of caregivers of cancer patients increased as the total score of home care practices and the provision of patient personal care sub-dimension scores increased (Table 4). Ugur et al. found that caregivers helped patients with their daily life activities and self-care, and organized the work related to the management of the house. Our findings are similar to studies [3, 6, 9].

The relationship between perceived social support and care burden

Caring for cancer patients affects the lives of family members and brings along many difficulties. For this reason, caregivers need to be supported by their families, feel that they are not left alone, and receive help regarding finance, information, and training as well as social and emotional support. Social support has significant effects on caregivers and
increases care burden [3, 9, 13]. Ye et al. state that the lack of social support has significant effects on caregivers and increases the burden of care [22]. In his research, Karaaslan found that caregivers who did not receive help from others and had to look after others had higher mean scores for the burden of care. Nurse caregiver supports the individual, helps him develop coping mechanisms, manages stress, and adapts to changing roles. In this context, it can take initiatives on issues such as informing caregivers about patient care, providing psychological-physical and social support, and activating existing resources [31, 32].

In our study, the effect of the variable of having to care for people other than cancer patients on the caregiver burden was found to be significant. This may be related to the patient population’s ability to perform home care activities. It was found that the performance status of the patients included in the study was generally good and they did not have any chronic diseases. In the literature, it is stated that the burden scores of the caregivers of patients with high physical competence are better than those of patients with high physical care burden [33].

In our study, a statistically significant difference was found between the care burden scores according to the total caregivers to the patient at home. Similarly, Karaaslan and Milbury et al. also found that caregivers with longer caregiving periods had higher burden scores; it has been determined that as the duration of caregiving increases, the burden of care scores increases [31, 32]. Especially Milbury et al., it was determined that caregivers experienced an increase in their physical, psychological, financial, and social problems after the 3rd and 6th months, and that they felt a decrease in the level of perceived social support was found to be high. The care burden mean score of the caregivers who provided care to patients with metastases was found to be significantly higher than that of the caregivers with patients with no metastases and the finding is in line with the study of Kaynar and Vural [5]. The finding is consistent with our study.

In our study, it was found that there was a weak and negative correlation between the perceived social support scores and caregiver burden scores (Table 3). In the advanced analysis, a significant correlation was found between the social support total scores and friend sub-dimension scores (Table 4). In a study conducted with patients with brain tumors and their caregivers, it was found that family members who received social support while giving care and were not hopeless had a lower care burden. Informing nurses and caregivers about the institutions and non-governmental organizations where they can get support and directing them to these organizations are of great importance in strengthening the social support systems of caregiver family members [32]. The reason for this is thought to be stemming from the fact that spouses, children, and other family members support each other in case of an illness according to the traditional Turkish family structure. This finding is similar to that of the study conducted by Kaynar and Vural [5]. According to the literature, the fact that caregivers have friends or families to discuss important things, getting help from them for home care activities as well as their provision of care to their patients and developing strategies collectively significantly reduce the care burden [3, 9, 10].

**Research limitations**

The limitation of the study is that caregivers of patients with a performance value of 20% or less were included, and the study was conducted in a single hospital with a limited sample size. In addition, the inclusion of patients with poor general condition in the study is another limitation.

**Conclusion**

It was found that the increase in home care practices of caregivers of cancer patients and the low level of perceived social support increase the burden of care. In this context, it is crucial to effectively identify the support needs of caregivers at home, to implement initiatives to reduce the care burden, and to provide guidance on the social support they can receive as well as counseling services. This study provides important new information on caregiver burden for individuals with cancer and offers three potential new scales, developed using a brief set of questions available in the public domain, to assess different aspects of caregiver burden. This present study is one of the first to provide nationally representative estimates for caregiver burden and associated predictors among caregivers of individuals with cancer. While further research is needed to develop the psychometric properties of these scales, they may be useful to assess burden among caregivers and to assist in developing and evaluating interventions to decrease caregiver burden.

**Supplementary Information** The online version contains supplementary material available at https://doi.org/10.1007/s00520-022-07266-1.

**Author contribution** Funding was acquired by Özlem Uğur (ÖU) and Tuha Ülgen (TÜ). TU and ÖU designed the study. All authors advised on data analysis and interpretation. ÖU wrote the first draft of the manuscript, which was reviewed and approved by all author.

**Data availability** Data are held securely by the research team and may be available upon reasonable request and with relevant approvals in place.

**Code availability** Not applicable.
Declarations

Ethics committee process This study was performed in line with the principles of the Declaration of Helsinki. Written consent was obtained from the Ethics Committee of a University Research and Application Hospital (ref no: 3546-GOA, 2017/23–43).

Consent to participate All participants provided written informed consent.

Consent for publication Not required.

Conflict of interest The authors declare no competing interests.

References

1. Sert HA (2015) Common problem of oncology patients? Relatives: caregiver burden. Türkiye Klinikleri Journal Of Internal Med Nurs-Special Topics 1(2):62–66 (Original work published in XXXI language name)
2. Turkey Cancer Statistics (2020) https://gco.iarc.fr/today/data/factsheets/populations/792-turkey-fact-sheets.pdf, p 1-2
3. Casado RP, Palomino-Moral PA, Martínez RM, Ramos-Morcillo AJ (2018) Social support and subjective burden in caregivers of adults and older adults: a meta-analysis. PLoS One 13(1):1–18. https://doi.org/10.1371/journal.pone.0189874
4. Hendrix CC, Bailey DE, Steinhauser KE, Olsen SMK, Lowman GS, Schwartz JA, Riedel FR, Keefe JF, Porter SL, Tulsy AJ (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
5. Kaynar Ö, Vural F (2018) Assessment of the caregiver burden of caregivers of colorectal cancer patients. Turk J Colorectal Dis 28:164–171. https://doi.org/10.4274/tjcd.26121
6. Uğur Ö, Elçiğil A, Arslan D, Sönmez A (2014) Responsibilities and difficulties of caregivers of cancer patients in home care. Asian Pac J Cancer Prev 15(2):725–729. https://doi.org/10.7314/APJC.2014.15.2.725
7. Altun İ (1998) Situations of difficulty in the caregiver role of relatives of patients, I. National Home Care Congress, Congress Summary Book pp: 71–78, Istanbul
8. Obayon HI, Goldzewig G, Sela-Oren T, Pizem N, Sela BG, Wolf son (2014) Attachment style, social support and finding meaning among spouses of colorectal cancer patients: gender differences. Palliat Support Care 13(3):527–535. https://doi.org/10.1017/S1478951513000024
9. Sun X, Ge J, Meng H, Chen Z, Liu D (2019) The influence of social support and care burden on depression among caregivers of patients with severe mental illness in rural areas of Sichuan, China. Int J Environ Res Public Health 16(11):1961. https://doi.org/10.3390/ijerph16111961
10. Mohamed N, Shah NQ, Kata EH, Sfakianos J, Given B (2021) Dealing with the unthinkable: bladder and colorectal cancer patients’ informal caregivers’ unmet needs and challenges in life after ostomies. Semin Oncol Nurs 37(1):15111. https://doi.org/10.1016/j.sonom.2020
11. Babağölçü E, Öz F (2003) The relationship between emotional and social problems of spouses caring for terminal cancer patients. J Nurs Res Dev 2:24–33 (Original work published in Turkish)
12. Dedeli Ö, Faddıoğlu Ç, Uslu R (2008) Investigation of functional status and perceived social support of individuals with cancer. Turkish J Oncol 23(3):132–139 (Original work published in Turkish)
13. Leung YPD, Chan YLH, Chiu CKP, Lo SKR, Lee LYL (2020) Source of social support and caregiving self-efficacy on caregiver burden and patient’s quality of life: a path analysis on patients with palliative care needs and their caregivers. Int J Environ Res Public Health 17(15):5457. https://doi.org/10.3390/ijerph17155457
14. Greer JA, Applebaum AJ, Jacobsen JC, Temel JS, Jackson AV (2020) Understanding and addressing the role of coping in palliative care for patients with advanced cancer. J Clin Oncol 38(9):915–925. https://doi.org/10.1200/JCO.19.00013
15. Halpern MT, Fiero MH, Bell ML (2017) Of caregiver activities and social supports on multidimensional caregiver burden: analyses from nationally-representative surveys of cancer patients and their caregivers. Qual Life Res 26(6):1587–1595. https://doi.org/10.1007/s11136-017-1505-9
16. Wolff JL, Spellman BC, Freedman VA, Kasper JD (2016) National profile of family and unpaid caregivers who assist older adults with health care activities. Internal Med 176(3):372–379. https://doi.org/10.1016/j.jamaintmed.2015.7664
17. Miller KD, Nogueira L, Mariotto BA, Rowland HJ, Yabroff RK, Alfano MC, Jemal A, Kramer LJ, Siegel LR (2016) Cancer treatment and survivorship statistics, 2016. CA Cancer J Clin 66(4):271–289. https://doi.org/10.3322/caac.21349
18. Zarit SH, Reever KE, Back-Peterson J (1980) Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 20:649–655
19. İnci, H (2006) Adaptation, validity and reliability of care burden scale to Turkish. Master Thesis, Pamukkale University, Institute of Health Sciences; Denizli, Turkey. (Original work published in Turkish)
20. Zimet GD, Dahlem NW, Zimet SG, Farley KG (1988) The multidimensional scale of perceived social support. J Pers Assess 52(1):30–41. https://doi.org/10.1207/s15327755jpa5201_2
21. Eker D, Arkar H, Yaldız H (2011) Factor structure, validity and reliability of the revised form of the multidimensional perceived social support scale. Turkish Journal of Psychol 12(1):17–25
22. Karnofsky DA, Burchenal JH (1949) The clinical evaluation of chemotherapeutic agents in cancer In: MacLeod CM (Ed), Evaluation of chemotherapeutic agents. Columbia Univ Press. p:196
23. T.C. Ministry of Family and Social Policies - Family and Community Services. General Directorate. Family Structure Research in Turkey 2011, pp: 238–244
24. Papastravrou E, Charalambous A, Tsangari H (2012) How do informal caregivers of patients with cancer cope: A descriptive study of the coping strategies employed. Eur J Oncol Nurs 16(3):258–263. https://doi.org/10.1016/j.ejono.2011.06.001
25. Seçilîk K, Avci D (2016) Care burden and affecting factors in caregivers of the elderly with chronic disease. SDU J Health Sci Inst 7(1):1–9 (Original work published in Turkish)
26. Türkoğlu N, Külcü D (2012) Effects of care burden of caregivers of cancer patients on their quality of life. Asian Pac J Cancer Prev 13(8):4141–4145. https://doi.org/10.7314/apjcp.2012.13.8.4141
27. Chua CK, Wu JT, Wong YY, Qu L, Tan YY, Neo HSP, Pang SG (2016) Caregiving and its resulting effects the care study to evaluate the effects of caregiving on caregivers of patients with advanced cancer in Singapore cancers. Cancers 8(11):2–21. https://doi.org/10.3390/cancers8110105
28. Schulz R, Sherwood PR (2008) Physical and mental health effects of family caregiving. J Soc Work Educ 44(3):105–113
29. Dionne-Odom JN, Hull JG, Martin MY, Lyons KD, Prescott TA, Tosteron T, Li Z, Akyar İ, Raju D, Bakitas MA (2016) Associations between advanced cancer patients’ survival and family caregiver presence and burden. Cancer med 5(5):853–862. https://doi.org/10.1002/cam4.653
30. Pearlin IL, Mullan TJ, Semple JS, Skaff MM (1990) Caregiving and the stress process: an overview of concepts and their measures. Gerontologist 30(5):583–594. https://doi.org/10.1093/geront/30.5.583

31. Robison J, Fortinsky R, Kleppinger A, Shugrue N, Porter M (2009) A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. J Gerontol B Psychol Sci Soc Sci 64:788–798

32. Malak TA, Dicle A (2008) Caregivers burden and affecting factors in patients with brain tumors. Turkish J Neurosurg 18(2):118–121 (Original work published in Turkish)

33. Ahn S, Romo RD, Campbell CL (2020) A systematic review of interventions for family caregivers who care for patients with advanced cancer at home. Patient Educ Couns 103(8):1518–1530. https://doi.org/10.1016/j.pec.2020.03.012

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