

## RESEARCH ARTICLE

# Caregiver Burden and Perceived Social Support among Caregivers of Patients with Cancer

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### Abstract

The purpose of this study is to describe the relationship between caregiver burden and perceived social support among caregivers of patients with cancer. The research was conducted in a university hospital in İzmir, Turkey. Eighty patient relatives who provided care service to patients with cancer who were admitted at hematology and oncology clinics participated in the study. The findings indicated that the care burden score was mild level. The mean of the perceived social support score was  $58.4 \pm 21.0$  supporting the conclusion that there is a weak and negative-direct relation between caregiver and perceived social support and that as the perceived social support increased, conversely, care burden decreased.

**Keywords:** Caregiver - caregiver burden - perceived social support - cancer.

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### Introduction

With its high ratios of mortality and morbidity, cancer is a challenging ailment adversely affecting the physical and emotional wellness of not only the patients but also their families (Terakye, 2011; Oksuz et al., 2013). As the number of people with cancer living their lives as patients demonstrate an upward trend each day globally, the number of family members who take care of them and live with them rises (Cameron et al., 2002).

Diagnosis of cancer and adoption of the caregiver role by family members are two parallel stages. Caregiver is the key person who supports the patient and usually provides the biggest care. A cancer patient in family forces the caregivers to face new circumstances into which they have to adapt. The longevity of this sickness state which impacts the whole family, life threatening effects of the ailment, inability of the patient to engage in work and social activities are a few of the reasons further climbing the responsibilities of the caregiver and transforming the roles within family (Oksuz et al., 2013; Akgul and Ozdemir, 2014). Caregivers themselves also go through certain physical, mental, social and financial troubles during the time they provide care to their patients (Terakye 2011). According to research, caregivers of cancer patients experience intense emotional and physiological stress during care-giving process; hence they themselves become vulnerable to physiological and psychological health problems (Kuscu et al., 2009; Yakar and Pinar 2013).

Zarit defines caregiver burden as physical, psychological, social or financial reactions that might emerge while providing care (Zarit, 1980) and it is

characterized with persistent worry, stress or negative experiences (Chiou et al., 2009). Many studies state that care-giver burden and health are negatively correlated (Chiou et al., 2009). Long-term care giving is a whole process impinging upon health, socio-financial state, psychological state which are all together indicators of life-quality (Silver and Wellman, 2002; Atagun et al., 2011). The pressure experienced by the caregiver may lead to such problems as depression, anxiety, burn-out syndrome, deteriorated physical health, social isolation and financial hardship. 60.6% of caregivers reported that they had no free-time; 78.8% of them explained that they felt exhausted, 84.9% reported that they experienced communication problems with the patient and 56.9% said they experienced financial hardships (Atagun et al., 2011).

All interpersonal relations which, have a major place in individuals' lives and provide emotional, physical and cognitive assistance to individuals whenever needed, are defined as "Social Support Systems" that support the state of health (Hogue, 1985). It has been emphasized that social support, which is conceptualized as the support given to any person in a troublesome or burdensome situation by family members, relatives as well as resources exerted by social connections, is effective in promoting physical health and feeling oneself good (Ardahan, 2006). There are certain studies reporting that caregivers receiving social support feel the less care burden and that there exists a negative- relation between the increase in social support and intensity of care burden (Edwards and Scheetz, 2002; Chiou et al., 2009). It has also been argued that social support level perceived by caregivers is among the primary factors affecting the health state of caregivers. For health

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professionals, it is highly significant to protect the health state of caregivers providing service to long-term patients in particular and to save them from the negative effects of treatment process.

Extensive assessments and initiatives focusing on this particular issue shall not only diminish the burden of caregivers but also it will save them from the negative effects of this process to some extent. This outcome shall reflect itself in the life-quality of the care giver as well as the patient. On accounts of lighting a torch in the planning, implementation and assessment of initiative towards decreasing caregivers' burden that the results obtained from the study considered dwelling on the relation between care burden and perceived social support will be useful.

Thus the main motive behind this research is to scrutinize the relation between care burden in caregivers patients with cancer and the level of the perceived social support.

## Materials and Methods

This is a descriptive and correlational study. The research was conducted between December 2013 - May 2014 in the hematology and oncology clinics within a university hospital in Izmir, Turkey.

The sample group of the study consisted of 80 relatives of patients receiving cancer treatment in the concerning clinic who provided care for patients over 18 and were themselves over 18, were willing to communicate, cooperate and participate in the study. Research data were collected by the researcher through face-to-face interviews at the hospital. Each interview took 15-20 minutes on average.

To proceed with the research, ethical board approval (ref: 2013-261), and written approvals of research institute and caregivers within the scope of research have been received.

### Data Collection

**Demographic Questionnaire:** Included descriptive questions regarding the age, gender, marital status of the caregivers; length of provided care in addition to questions concerning the age, gender and malignancy status of patients.

**ECOG Performance Status Scale:** This was used to assess how a patient's disease is progressing, how the disease affects daily life abilities of the patient, and to determine the appropriate treatment method and prognosis. With respect to the dependency level of patients, ECOG performance scale ranged from "0" to "5". "0" indicated that the patient was asymptomatic, fully active, able to perform pre-disease tasks with no restriction at all; "1" indicated that the patient was symptomatic but still fully on foot; "2" indicated that the patient was symptomatic and was bedded less than 50%; "3" indicated that the patient was symptomatic and was bedded more than 50%; "4" indicated that the patient was fully bedded; "5" indicated that the patient was "dead".

**Zarit Caregiver Burden Interview (ZBI):** This was developed in 1980 by Zarit and Zarit (1990). Validity and reliability study of its Turkish version was conducted in 2008 by Inci and Erdem and the Cronbach Alpha Value is in the range of 0.87-0.99. This scale measuring the effect of care-giving on an individual's life includes 22 statements. This is a Likert type scale evaluating on the basis of 0 to 4 points as "never", "rarely", "sometimes", "frequently", "always". The lowest score to be received from the scale is 0 and the highest is 88. The items included in the scale focus mainly on the social and emotional domains and the higher the score is, the more severe the problem is. In scoring, 0-20 means "no care burden", 21-40 "low care burden", 41-60 "medium care burden" and 61-88 means "heavy care burden" (Inci and Erdem, 2008).

**Multidimensional Scale of Perceived Social Support (MSPSS):** This is a scale type subjectively evaluating the qualities of social support gathered from three dissimilar sources. The validity and reliability study of the Turkish version was carried out in 2001 by Eker et al. The scale consists of three subdimensions as social support perceived "from family", "from friends" and "from significant someone" and the reliability scores are 0.89 on the whole scale and 0.85 on the subdimensions. MSPSS comprises 12 items. Each item is graded by employing a 7-interval scale. The practitioner could give minimum 1 point to a statement not agreed, maximum 7 to a statement agreed. As the score given to each item increased so did the level of perceived social support. The minimum score to be received from the total scale is 12 and maximum score is 84, whereas the minimum score to be received from subdimensions is 4 and maximum score is 28 (Eker et al., 2001).

### Data analysis

Data analysis has been conducted on Statistical Package for Social Science (SPSS) 21.0 package program. means, standard deviation, and percentages were used. In order to determine the features of caregivers and caretaker patients and to measure caregiver burden and perceived social support score. In designating the relation between caregivers burden and perceived social support correlation analysis; in detecting the impact of ECOG performance score on care burden Kruskal Wallis analysis was implemented.

## Results

67.4% of the caregivers constituting the scope of the current study are in the 35-64 age group (mean= 45±14.45), 67.5% are females, 73.7% are married. 37.4% of the caregivers are spouses and 37.4% of them have been providing service for 1-2 years.

50% of the caretaker patients are in the 35-64 age group and 51.2% are males. 42.6% of the patients were diagnosed with a hematologic malignancy, 18.8% were diagnosed with uterus, breast or ovary, 12.5% with lungs, 22.5% with prostate, colon or stomach malignancy. As for ECOG performance score of patients it was identified that

**Table 1. The Mean ZBI Scores of the Caregivers**

| Care Burden        | Range       | n  | %    |
|--------------------|-------------|----|------|
| No care burden     | 0-20        | 15 | 18.7 |
| Mild care burden   | 21-40       | 40 | 50   |
| Medium care burden | 41-60       | 19 | 23.8 |
| Heavy care burden  | 61-88       | 6  | 7.5  |
| Total              | 34.16±16.39 | 80 | 100  |

**Table 2. The Mean MSPSS Scores of Caregivers**

| MSPSS subdimensions                               | Mean±SD    | Min-Max |
|---|------------|---------|
| Perceived social support from significant someone | 20.04±8.2  | 4-28    |
| Perceived social support from families            | 21.01±7.65 | 4-28    |
| Perceived social support from friends             | 17.02±8.5  | 4-28    |
| Total   | 58±20.95   | 12-84   |

8.8% were “0”, 21.3% were “1”, 28.6% were “2”, 17.5% were “3”, 23.8% were “4”.

It was found that caregivers' ZBI score means were 34.16±16.39. 50% had “mild” care burden, 23.8% had “medium” care burden, 7.5% had “heavy” care burden. The ratio of caregivers with “no care burden” was 18.7% (Table 1).

As for ZBI score means of caregivers, it was found that the ones providing care to patients with “0” ECOG score had 20.71±7.15; those providing care to patients with “1” ECOG score had 29.35±9.38; the ones providing care to patients with “2” ECOG score had 34.65±20.96; those providing care to patients with “3” ECOG score had 33.57±15.05; and those providing care to patients with “4” ECOG score had 43.26±14.29. analysis showed that there was significant differentiation in the care-burden score means received according to ECOG performance scale ( $X^2:14,049, p:0,007$ ).

MSPSS total means of caregivers is 58.43±20.95. Subdimensional score means are; 20.4±8.2 in “perceived social support from someone special” dimension, 21.01±7.65 in “perceived social support from families” dimension, 17.02±8.5 in “perceived social support from friends” dimension (Table 2).

MSPSS total means of caregivers is 58.43±20.95. Subdimensional score means are; 20.4±8.2 in “perceived social support from significant someone” dimension, 21.01±7.65 in “perceived social support from families” dimension, 17.02±8.5 in “perceived social support from friends” dimension (Table 2).

A negative-directed, weak relation was found between ZBI & MSPSS score means of the caregivers ( $r=-0.253, p<0.05$ ). A weak negative relation was found between ZBI score and perceived social support from “someone special” ( $r=-0.247, p<0.05$ ), and “friends” ( $r=-0.290, p<0.05$ ) which are among MSPSS subdimensions and care burden while no relation could be identified between perceived social support from “family” and care burden ( $p>0.05$ ).

## Discussion

In the present study on the relation between care burden of caregivers to patients with cancer and the level

of perceived social support; care burden of caregivers of cancer patients was detected as “mild”. In terms of care burden classification, 50% of caregivers had “mild” care burden, 23.8% had “medium”, and 7.5% had “heavy” care burden. Similarly, in the study of Yildirim et al. (2013) parallel results were found out and it was established that caregivers' burden levels were low-, which might be attributed to traditional Turkish culture. In Turkish culture, it is only natural for relatives to take care of the needy patients, and caregivers deem this practice as a natural duty and responsibility. Caregivers, although they face hardship during this care process, are expected to treat their patients at home. This may mean that during care giving process, caregivers have low awareness on the care burden or they fully submit to their care burden as a consequence of learned helplessness.

In similar studies, care burden score means were found as follows: 21.29±12.00 in mothers providing care for children with cancer of their own (Ozdemir et al., 2009); 28.70±16.14 in caregivers of patients receiving three and higher number of chemotherapies; 21.75±9.66 in caregivers of patients receiving less than three chemotherapies (Oksuz et al., 2013) and similarly 36.65±11.21 in caregivers of patients with cancer (Turkoglu and Kilic 2012). Caregiver burden results obtained from our study showed similar findings to the research conducted by Turkoglu, Kilic & Oksuz et al. to detect burdens of caregiving to patients receiving more than three cures of chemotherapy. However, according to Ozdemir et al., our findings were higher compared to the caregiving burden to patients receiving three and fewer cures of chemotherapy. The low perceived care burden among mothers of children with cancer is attributed to their lack of feeling burden on accounts of motherly instincts and that the dependency level among those receiving fewer than three cures of chemotherapy is lower.

It can be seen in the related literature on care burden that dependency level of treated patients with cancer is also influential on the level of care burden (Morimoto et al., 2003; Grov et al., 2006). Atagun et al. (2011) report that as the dependency level of patient climbs up, negative experiences of care giver concordantly rise which in turn pushes care givers' burden higher. Likewise it was found that higher levels of care burden have been identified among caregivers of the patients with high level of dependency. It is considered that as the dependency condition of patients increases, they demand assistance in even the simplest tasks such as eating, drinking and bathroom use, which eventually increases burdens of caregivers. In their study, Zaybak et al. (2012) have also found that people who provide care to highly dependent patients exhibit greater burdens of care. Chiou et al. (2009) have also identified parallel results in their study and concluded that there is a direct proportion between dependency in daily- life activities and perceived care burden level. As demonstrated by all these findings, the greater the patient's dependency on caregiver is the greater the perceived level of care burden becomes.

It has been a long-established assumption that social relations play a vital role in assisting people to cope with challenges in life and resist the negative effects of stress

(Ardahan, 2006). In the study, perceived social support score means of caregivers are;  $58,43 \pm 20,95$  in total scale, and between  $21,01 \pm 7,65$  and  $17,02 \pm 8,5$  in subdimensions. These findings echo research results obtained from caregivers of patients with cancer in Turkey. (Kuscu et al., 2009; Kutluturkan et al., 2012; Eser and Beduk, 2014). Remembering that the lowest score to receive from MSPSS is 12 and the highest is 84, in our research results, it can be argued that social support level perceived by caregivers is above the average.

It has been established by the present study that there is negative, weak relation between ZBI and MSPSS score means of caregivers. a negative-directed, weak relation was found between support from "someone special" and "friend" subdimensions and care burden, while no relation could be detected between "family" support and care burden. These findings reveal that among the caregivers included in the present study, perceived social support at subdimensions other than family and on the total scale produce effective results in diminishing their care burdens. Relevant literature studies also report parallel results. Chiou et al. (2009) have reported that caregivers who receive social support feel mild care burden and as the perceived social support increases a downward inclination is observed in care burden. Cooper et al. (2013) have also noted that informal social support is closely related with care burdens of caregivers. Goldstein et al. (2004) have remarked that caregivers who have small social support experience greater levels of care burden.

It is of no question that family support plays a vital role in helping individuals cope with stressful or worrisome situations (Sahin and Tan, 2012). Nonetheless, in the present study, perceived social support from family was not influential on care burden. There are a number of explanations for this outcome: The first one is related to traditional social structure in Turkey. In this structure, family concept and cooperation among family members and even relatives bear great value and familial support is a lifetime experience. However, there are some reports indicating that over-dependent family relations may increase the level of emotional load as an outcome of traditional family structure (Kuscu et al., 2009) and the attempts of social circle to provide support may occasionally be perceived by the receiver as their attempts to control and interfere, which might in turn affect the individual negatively and increase his/her level of stress (Karakoc and Yurtsever, 2008). In the present study as well family support was found to have no soothing effect on care burden, which might indicate that this support is perceived by the caregiver as their attempts to dominate and control/interfere. One other explanation is that support received from friends or someone special can provide a more comforting effect. Indeed Barber (2013) in his study determined that social support of friends has a positive effect in enhancing motivation of caregivers providing service to patients with cancer. It is of common knowledge that people feel themselves mentally closer to people from their age group. In that case while social support received from family may not affect care burden score, social support received from friends and someone special may leave an effect on the score.

In addition to all, DÖkmen (2012) claims that it is also possible that social support will fall short in softening the results of caregiver burden. Therefore, aside from providing the support needs of caregivers by their families, friends, partners or someone special, it is also necessary to meet their needs in a systematic and directly relevant way on an institutional base to minimize the negative effects of caregivers' burden.

In conclusion, as a result of the present study on the relation between the care burden of caretakers of patients with cancer and their perceived social support, it has been found that care burden in caregivers of patients with cancer is mild; caregivers who provide service to dependant patients have greater level of burden; and perceived social support from "friends" and "someone special" has a decreasing effect on care burden. In the light of all these findings, in order for caregivers not to be negatively affected physiologically or psychologically due to heavy care burden, care givers should be informed about the potential burden and consequences of the care giving process and adaptation of caregivers into care processes should be monitored closely. Throughout this process, the assessment of social support systems in coordination with care givers may provide effective results in enhancing caregivers' awareness on this issue. As another solution, it is deemed necessary to provide professional consultancy services to caregivers on the issue of social support and encourage them to receive such services..

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