

Comparison of stress coping attitudes in caregivers for cancer and non-cancer patients on palliative care

Habibe İnci¹, Oğuzhan Kılınçel², Fatih İnci³, Fatih Karataş³, Didem Adahan¹

¹Department of Family Medicine, Faculty of Medicine, Karabük University, Turkey

²Department of Psychiatry, Sakarya Education and Research Hospital, Turkey

³Department of Medical Oncology, Faculty of Medicine, Karabük University, Turkey

Abstract

Introduction: Changes in the social and emotional state of patient caregivers are associated with the individual care burden of the patient rather than the diagnosis of the patient. Our aim was to compare the stress levels and coping attitudes of caregivers who give palliative care to patients with cancer and non-cancer.

Material and methods: This non-randomised, controlled study included caregivers providing palliative care to patients diagnosed with cancer and non-cancer in the palliative care unit. The participants were evaluated in respect of age, gender, duration of caregiving, relationship to the patient, marital status, level of education, occupation, psychiatric history, chronic disease history, and smoking status using a data collection form, and the means of coping with stress with the Coping Orientation to Problems Experienced (COPE) scale.

Results: Evaluation was made of a total of 80 participants comprising 40 (50%) caregivers of patients diagnosed with cancer and 40 (50%) caregivers of patients not diagnosed with cancer. Female gender, smoking, and caregiving duration were significantly higher ($p = 0.009$, $p = 0.001$, $p = 0.001$, respectively) and educational level was lower ($p = 0.022$) in the caregivers of non-cancer patients. In the subscales of COPE, the scores of suppressing other activities ($p < 0.001$), mental disengagement ($p = 0.001$), and emotion-focussed coping ($p = 0.007$) were higher in the group of caregivers of non-cancer patients.

Conclusions: Because the duration of the cancer patient's need for care is shorter than that of non-cancer patients, this may cause the caregivers of cancer patients to be less able to adapt to the stressful process they experience than the caregivers of non-cancer patients.

Key words: cancer, caregiver, palliative care, patients.

Address for correspondence:

Habibe İnci, MD, Department of Family Medicine, Faculty of Medicine, Karabük University, Karabük, Turkey, phone: +903704158000, e-mail: drhbesler@hotmail.com

INTRODUCTION

With progression of a disease requiring palliation, physical activity is restricted, so a rehabilitation process is required including efforts to provide the highest level of emotional, psychological, occupational, and social potential. This process has negative effects in emotional, social, and physical terms on the caregivers, the majority of whom are family members [1]. Although the stress of caregivers is mostly mild, as these individuals are generally a member of the family, it has been reported that they experience more anxiety, depression, stress, fatigue, role conflict, and social isolation than the patient, and this increases the risk of physical disease [2]. To eliminate the negative effects of these factors, overcome them, and protect themselves psychologically, individu-

als develop some coping mechanisms to deal with stressful events. Social and personal resources make it easier to adapt to critical life events and increase the effectiveness of dealing with stressful and traumatic situations [3].

The aim of this study was to evaluate and compare the sociodemographic characteristics, stress, and coping mechanisms of caregivers to cancer and non-cancer patients receiving palliative care.

MATERIAL AND METHODS

This non-randomised, controlled study included caregivers providing palliative care to patients diagnosed with cancer and non-cancer in a palliative care unit between November and December 2018.

The participants were evaluated in respect of age, gender, duration of caregiving, relationship to the patient, marital status, level of education, occupation, psychiatric history, chronic disease history, and smoking status using a prepared questionnaire. The stress coping attitudes were evaluated with the Stress Coping Scale (Coping Orientation to Problems Experienced – COPE).

The COPE scale was developed by Carver *et al.* [4] to determine the coping strategies used in stressful situations. The validity and reliability studies of the form in Turkish were conducted by Ağargün *et al.* [5]. The scale has 60 items in 15 subscales with four items in each, which are answered with a four-point Likert-type response (1 – I never do that, 2 – I do not do that often, 3 – I sometimes do that, 4 – I generally do that). Each subscale provides information about a separate coping attitude.

The 15 coping attitudes of the subscales are as follows: problem-focussed coping (1. Active coping, 2. Disengagement, 3. Planning, 4. Using instrumental social support, 5. Suppression of other activities), emotional-focussed coping (6. Positive re-interpretation and development, 7. Religious coping, 8. Joking, 9. Using emotional social support, 10. Acceptance), and non-functional coping (11. Behavioural disengagement, 12. Substance use, 13. Denial, 14. Mental disengagement, 15. Focussing on the problem and venting emotions) [5].

In the evaluation, each subscale can be scored from 4 to 16 points. The total number of points of the first five subscales represent problem-focussed coping, subscales 6-10 represent emotional-focussed coping, and subscales 11-15 represent non-functional coping. Higher points in any of the subscales indicate that the individual uses that form of coping more.

Statistical analysis

Data obtained in the study were analysed statistically using SPSS v. 22.0 software. In the comparison between the groups, Student's *t*-test was applied to non-categorical data with normal distribution, and the Mann-Whitney *U*-test was applied to non-parametric data. Categorical data were compared using the chi-square test. A value of $p < 0.05$ was accepted as statistically significant.

Approval for the study was granted by the Non-Interventional Clinical Research Ethics Committee of Karabük University (approval no. 10/22, 31.10.2018). Written, informed consent was obtained from all the study participants.

RESULTS

Evaluation was made of a total of 80 subjects, comprising 40 (50%) caregivers of cancer patients

and 40 (50%) caregivers of non-cancer patients. Patients had clinical features that were not curable with current treatment methods. Considering the clinical-pathological features, the cancer patient group members were expected to end their lives earlier than the non-cancer patient group. The cancer patient group consisted of advanced-stage patients who could not receive active chemotherapy and only received supportive therapy for a variety of reasons (comorbidity, exhaustion of all drug options, patient treatment rejection) in the oncology department. Fourteen (17.5%) of the cancer patients had colorectal-, 14 (17.5%) had breast-, and 12 (15%) had gastric and biliary tract-related tumours. Of the non-cancer palliative patients, 13 (16.2%) had diseases related to the respiratory system, 13 (16.25%) had cerebrovascular system, 10 (12.5%) had Alzheimer's disease, and 4 (5%) had Parkinson's disease (17.5%)

The sociodemographic characteristics of the participants are shown in Table 1. The caregivers of cancer patients were younger than the caregivers of non-cancer patients (44 ± 14.8 years vs. 56 ± 14.8 years, $p < 0.001$). In respect of gender, there was a higher rate of female gender in caregivers of non-cancer patients compared to cancer patients (80% [$n = 32$] vs. 50% [$n = 20$], $p = 0.009$). The duration of caregiving was statistically significantly longer at mean seven years for those caring for non-cancer patients compared to two years for the group of caregivers to cancer patients ($p < 0.001$).

In both groups the caregiver was a family member. While the caregivers of non-cancer patients were the spouse of the patient in 42.5% of cases and the child in 37.5%, in the group of caregivers of cancer patients, the carer was the spouse of the patient in 45% of cases and the child in 40% ($p = 0.92$). Among the caregivers, 87.5% of the caregivers of cancer patients were married, and 85% of the non-cancer patient caregivers. The education level of the caregivers of cancer patients was numerically statistically higher than that of the caregivers of non-cancer patients ($p = 0.069$). In the analysis of occupations, there was a statistically significantly higher rate of housewives in the group of caregivers of non-cancer patients (75% vs. 37.5%, $p < 0.010$). None of the caregivers in either group had a history of psychiatric disease or chronic disease. There were statistically significantly more cigarette smokers in the group of caregivers of non-cancer patients ($p < 0.001$) (Table 1).

In the evaluation of the COPE scale, the mean total points were 162.25 ± 21.63 for the caregivers of cancer patients and 169.25 ± 12.11 for the caregivers of non-cancer patients, and the difference was not statistically significant ($p = 0.093$) (Table 2). In the comparisons of points for problem-focussed coping, no difference was seen between the groups in respect of active coping, disengagement, plan-

Table 1. Sociodemographic and clinical characteristics of the participants

Variables	Caregivers of cancer patients	Caregivers of non-cancer patients	P-value
Age (years), median (min-max)	44 (21-73)	56 (21-72)	0.001
Gender, n (%)			0.009
Female	20 (50)	32 (80)	
Male	20(50)	8 (20)	
Duration of caregiving (years), median (min-max)	2 (1-4)	7 (4-11)	< 0.001
Relationship to patient, n (%)			0.927
Child	16 (40)	15 (37.5)	
Spouse	18 (45)	17 (42.5)	
Daughter-in-law	4 (10)	6 (15)	
Sibling	2 (5)	2 (5)	
Marital status, n (%)			1
Married	35 (87.5)	34 (85)	
Single	5 (12.5)	6 (15)	
Level of education, n (%)			0.069
Primary school	19 (47.5)	29 (72.5)	
Middle school, High school	13 (32.5)	6 (15)	
University	8 (20)	5 (12.5)	
Level of education, n (%)			0.022
Primary school	19 (47.5)	29 (72.5)	
Others	29 (52.5)	11 (27.5)	
Occupation, n (%)			0.010
Housewife	15 (37.5)	30 (75)	
Manual worker	8 (20)	1 (2.5)	
Clerical worker	4 (10.4)	3 (7.5)	
Retired	3 (7.5)	2 (5)	
Others	10 (25)	4 (10.4)	
Psychiatric history, n (%)			N/A
Present	0 (0)	0 (0)	
Absent	40 (100)	40 (100)	
Chronic disease history, n (%)			N/A
Present	0 (0)	0 (0)	
Absent	40 (100)	40 (100)	
Cigarette smoking, n (%)			< 0.001
Smoker	11 (27.5)	29 (72.5)	
Non-smoker	29 (72.5)	11 (27.5)	

ning, and using instrumental social support, while the subscale points for suppression of other activities were determined to be statistically significantly higher for the caregivers of non-cancer patients ($p < 0.001$).

In the emotional-focussed coping section, the points of the caregivers of the non-cancer patients were statistically significantly higher than those of the caregivers of cancer patients in respect of pos-

itive re-interpretation and development, religious coping, joking, and the use of emotional social support ($p = 0.007$). No statistically significant difference was observed between the groups in respect of acceptance. In the non-functional coping section, no statistically significant difference was observed between the groups in respect of behavioural disengagement, substance use, denial, focussing on the problem, and venting emotions. The mental disen-

Table 2. Comparisons of the COPE subscale scores of the participants

COPE subscale points	Caregivers of cancer patients median (min-max)	Caregivers of non-cancer patients median (min-max)	P-value
1. Active coping	14 (7-16)	13 (11-16)	0.731
2. Disengagement	11 (6-16)	11 (9-14)	0.290
3. Planning	14 (6-16)	14 (9-16)	0.493
4. Use of instrumental social support	14 (8-16)	13 (10-16)	0.391
5. Suppression of other activities	11 (5-16)	13 (11-16)	< 0.001
6. Positive re-interpretation and development	14 (8-16)	14 (11-16)	0.973
7. Religious coping	14.5 ±2.5	15.1 ±1.47	0.221
8. Joking	5.5 (4-15)	8 (4-16)	0.113
9. Use of emotional social support	13 (8-16)	14 (9-16)	0.278
10. Acceptance	12.5 (4-16)	12 (11-14)	0.670
11. Behavioural disengagement	6 (4-13)	6 (4-12)	0.323
12. Substance use	5.08 ±2.04	4.63 ±1.48	0.311
13. Denial	9 (4-15)	8 (4-11)	0.496
14. Mental disengagement	10 (5-16)	12 (8-14)	0.001
15. Focussing on the problem and venting emotions	12 (5-16)	10 (8-16)	0.645
COPE-P: Problem-focussed coping	62.8 ±7.49	65.5 ±5.35	0.079
COPE-E: Emotion-focussed coping	59.20 ±7.62	63.01 ±4.44	0.007
COPE-NF: Non-functional coping	41.10 ±9.51	40.93 ±5.11	0.919
COPE-T: Total coping points	162.25 ±21.63	169.25 ±12.11	0.093

COPE – Coping Orientation to Problems Experienced

agement points were determined to be statistically significantly higher for the caregivers of non-cancer patients compared to the caregivers of cancer patients ($p = 0.001$) (Table 2).

While there was no correlation between emotion-focused coping score and mental disengagement score with age of caregivers ($p = 0.134$, $p = 0.163$, respectively), there was a positive correlation with the duration of care ($p = 0.003$, $r = 0.333$; $p = 0.003$, $r = 0.324$, respectively). There was no relationship between gender and smoking, mental disengagement score, and emotion-focused coping score ($p = 0.955$, $p = 0.300$ and $p = 0.123$, $p = 0.678$, respectively). While there was no relationship between occupational and mental disengagement scores ($p = 0.120$), there was a difference between retired and clerical worker groups according to emotional focused coping scores among occupational groups ($p = 0.003$) (Table 3).

DISCUSSION

In this study, it was determined that the caregivers in both groups were family members and the majority were the spouse or child of the patient. Individuals providing patient care experience physical

and emotional tensions for reasons such as fulfilling responsibilities both at home and outside, economic difficulties, physical and emotional stress causing self-neglect, and lack of free time. In a study by Lovely *et al.*, it was reported that 82% of caregivers of palliative care cancer patients experienced a moderate level of stress and 18% experienced a severe level [6].

When the caregivers in the current study were compared in respect of sociodemographic characteristics, the majority of the caregivers of non-cancer patients were female and no significant difference was found between the genders of the caregivers of cancer patients. In the current study, the caregivers of the non-cancer patients were older, had a lower level of education, and almost all were housewives. This result could be due to the majority of non-cancer palliative care patients being older and hence their spouses are older and do not work. These results can also be attributed to this patient group being bedridden because of cerebrovascular and neurological diseases and geriatric problems, and because family members undertake the continuous care that is required.

The duration of caregiving of those caring for non-cancer patients was determined to be longer compared to the caregivers of cancer patients.

Table 3. Post-hoc analysis for relations between COPE-E scores and occupations

Occupation (A)	Occupation (a)	Mean difference (Aa)	Standard error	P-value
Housewife	Manual worker	6.044*	2.198	0.007
	Clerical worker	5.013*	2.445	0.044
	Retired	-5.844*	2.837	0.043
	Others	1.584	1.842	0.393
Manual worker	Housewife	-6.044*	2.198	0.007
	Clerical worker	-1.032	3.033	0.735
	Retired	-11.889*	3.357	0.001
	Others	-4.460	2.572	0.087
Clerical worker	Housewife	-5.013*	2.445	0.044
	Manual worker	1.032	3.033	0.735
	Retired	-10.857*	3.524	0.003
	Others	-3.429	2.786	0.222
Retired	Housewife	5.844*	2.837	0.043
	Manual worker	11.889*	3.357	0.001
	Clerical worker	10.857*	3.524	0.003
	Others	7.429*	3.136	0.020
Others	Housewife	-1.584	1.842	0.393
	Manual worker	4.460	2.572	0.087
	Clerical worker	3.429	2.786	0.222
	Retired	-7.429*	3.136	0.020

COPE – Coping Orientation to Problems Experienced

The proportion of cigarette smokers was determined to be statistically significantly higher in the caregivers of non-cancer patients compared to the caregivers of cancer patients. This could be related to this group of caregivers being exposed to chronic stress for longer periods, and previous studies have reported a high rate of cigarette smoking in those exposed to chronic stress [7].

Previous studies have shown that when there is a patient in the family, the roles within the family change as they experience fatigue, anxiety, and social life changes; especially female family members who try to take on several roles and responsibilities at the same time experience “care burden” and “care stress” with the care of the patient and neglect their own personal needs [8, 9]. The psychological effect of stress on quality of life is seen in the form of increased emotional distress, anxiety and/or depression, hopelessness, a feeling of loss of control, and difficulty coping [10].

Although coping attitudes have been investigated in several diseases, no similar study could be found in which comparisons were made of the coping attitudes to long-term stress of the caregivers of patients in two disease groups. In our study, the coping attitudes of the caregivers of palliative care patients with and without cancer were evaluated with the COPE points, and while no significant dif-

ference was determined between the total points of the two groups, significant differences were seen in the subscales. In the COPE subscales, the suppression of other activities, mental disengagement, and emotion-focussed coping attitude points were higher in the group of caregivers of non-cancer patients than for the caregivers of cancer patients.

The care of a patient with non-cancer chronic diseases and geriatric problems is a more complex and longer process than for a cancer patient. This requires caregivers to constantly face and overcome problems. In our study, the fact that the caregivers of non-cancer patients had higher points in the subscales of suppression of other activities, mental disengagement, and emotion-focussed coping than the caregivers of cancer patients can be explained by the development of adaptation in this chronic process. In the post-hoc analysis, a positive correlation was found between the scores of mental disengagement and emotion-focused coping scores with the duration of caregiving in our study. In addition, a relationship was found between occupational and emotion-focused coping scores. The duration of care of the caregivers of cancer patients was shorter and the capability to develop adaptation may be lower in the period of stress experienced as a result of progression with medical complications because cancer has a rapid course. In a study by Karabulutlu *et al.* [11],

the coping attitude most used by caregivers who are family members of cancer patients was determined to be active planning, and the least used was avoiding isolation.

Religious belief is an important factor in coping with stress. In both groups of the current study, the religious coping subscale points were high, with no significant difference determined between the groups. In 2013, Anne Vandenhoeck emphasised the need for caregivers to be educated and competent in spiritual care [12]. In the study of cancer patient caregivers by Karabulutlu *et al.* [11], the scores of seeking refuge in religious faith were determined to be high.

In a study by Lovely *et al.* [6] of the caregivers of palliative patients with cancer, it was determined that the positive coping attitudes adopted were the use of humour, religious belief, planning, and active coping methods, and the negative coping attitudes most commonly were distracting oneself, denial, behavioural disengagement, and substance use.

Undertaking patient care of a close relative causes physical, psychological, emotional, social, and economic problems in addition to positive developments such as increased emotional closeness and affection, personal development, improvement in close relationships, satisfaction, social support from others, and self-confidence [9]. Efforts to support the mental and physical coping capabilities of caregivers can make this difficult process easier [13]. Previous studies have shown that psychosocial support given to family members providing patient care makes a positive contribution to their wellbeing, positive perceptions of their role, and quality of life [14]. Carers may have negative effects, including depression, social isolation, sleep deprivation, financial burden, and significant changes in their lives [15]. Communication of health resources should be improved to support burden of caregivers [16]. It is necessary to assess the needs of caregivers, identify appropriate support services, provide high-quality care, and ensure caregiver satisfaction [17]. The complexity of end-of-life communication in cancer carers is increasing [18]. Cancer caregivers play an important role in cancer care [19]. There may be additional findings such as cardiac findings in cancer patients [20]. The first stage of treatment is the correct diagnosis [21]. In the literature, it has been reported that cancer patients have higher levels of depression and anxiety than in general society [22].

Cancer patient caregivers have an emotional response to the disease, and so psychological health can be more affected because it is more stressful to care for a cancer patient. Moreover, as the disease progresses and the care process is prolonged, the physical and psychological burden on the caregiver increases [23].

The limitation of our study is that the number of participants is low, and our study was single-centred. Because the study areas of the authors are connected with cancer and non-cancer patients, studies have been conducted between these two groups. Because the survival time of cancer patients is shorter than for other diseases, the need for care is shorter.

In conclusion, because the duration of the cancer patient's need for care is shorter than that of non-cancer patients, this may cause the caregivers of cancer patients to be less able to adapt to the stressful process they experience than the caregivers of non-cancer patients. Therefore, adaptation programs should be arranged for caregivers of cancer patients. In order to better understand the subject, there is a need for studies about the patient group with wide participation and different types of cancer.

The authors declare no conflict of interest.

REFERENCES

- Porter LS, Keefe FJ, Garst J, et al. Caregiver-assisted coping skills training for lung cancer: results of a randomized clinical trial. *J Pain Symptom Manage* 2011; 41: 1-13.
- Chen HY, Boore JR. Living with a relative who has a spinal cord injury: a grounded theory approach. *J Clin Nurs* 2009; 18: 174-182.
- Basińska MA, Sołtys M. Personal resources and flexibility in coping with stress depending on perceived stress in a group of cancer patients. *Health Psychology Report* 2020; 8: 107-119.
- Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. *J Pers Soc Psychol* 1989; 56: 267-283.
- Agargün MY, Beşiroğlu L, Kıran ÜK, et al. COPE (Başa Çıkma Tutumlarını Değerlendirme Ölçeği): Psikometrik Özelliklere İlişkin Bir Ön Çalışma [The psychometric properties of the COPE inventory in Turkish sample: a preliminary research]. *Anadolu Psikiyatri Dergisi* 2005; 6: 221-226.
- Lovely A, Linu SG, Tessa TJ. Stress, coping, and lived experiences among caregivers of cancer patients on palliative care: A mixed method research. *Indian J Palliat Care* 2018; 24: 313-319.
- Salgado-García FI, Zuber JK, Graney MJ, et al. Smoking and smoking increase in caregivers of Alzheimer's patients. *Gerontologist* 2013; 55: 780-792.
- Mukwato KP, Mweemba P, Makukula MK, et al. Stress and coping mechanisms among breast cancer patients and family caregivers: a review of literature. *Med J Zambia* 2010; 37: 40-45.
- Gitterman A. *Handbook of social work practice with vulnerable and resilient populations*. Columbia University Press 2014.
- Northouse LL, Katapodi MC, Song L, et al. Interventions with family caregivers of cancer patients: meta analysis of randomized trials. *CA Cancer J Clin* 2010; 60: 317-339.
- Karabulutlu EY. Coping with stress of family caregivers of cancer patients in Turkey. *Asia Pac J Oncol Nurs* 2014; 1: 55-60.
- Vandenhoeck A. Chaplains as specialists in spiritual care for patients in Europe. *Polskie Archiwum Medycyny Wewnętrznej* 2013; 123: 552-557.
- Blumenthal JA, Keefe FJ, Babyak MA, et al. Caregiver-assisted coping skills training for patients with COPD: background,

- design, and methodological issues for the INSPIRE-II study. *Clin Trials* 2009; 6: 172-184.
14. Hudson PL, Remedios C, Thomas K. A systematic review of psychosocial interventions for family carers of palliative care patients. *BMC Palliat Care* 2010; 9: 17.
 15. Ugalde A, Gaskin CJ, Rankin NM, et al. A systematic review of cancer caregiver interventions: Appraising the potential for implementation of evidence into practice. *Psychooncology* 2019; 28: 687-701.
 16. Wittenberg E, Xu J, Goldsmith J, et al. Caregiver communication about cancer: development of a health resource to support family caregiver communication burden. *Psychooncology* 2019; 28: 365-371.
 17. Shin DW, Park JH, Shim EJ, et al. The development of a comprehensive needs assessment tool for cancer caregivers in patient – caregiver dyads. *Psychooncology* 2011; 20: 1342-1352.
 18. Shin DW, Cho J, Kim SY, et al. Discordance among patient preferences, caregiver preferences, and caregiver predictions of patient preferences regarding disclosure of terminal status and end of life choices. *Psychooncology* 2015; 24: 212-219.
 19. Wittenberg E, Goldsmith JV, Kerr AM. Variation in health literacy among family caregiver communication types. *Psychooncology* 2019; 28: 2181-2187.
 20. Beşler MS, Canpolat U. Cardiac metastasis mimicking acute ST-elevation myocardial infarction. *Anatol J Cardiol* 2019; 22: E1-E2.
 21. Parlak S, Beşler M. Ankara bombing: distribution of injury patterns with radiological imaging. *Pol J Radiol* 2020; 85: 90-96.
 22. Ersoy S, Habibe İNCİ, Fatih İNCİ, et al. Depression, anxiety and coping strategies in cancer patients: a case control study. *Ankara Med J* 2019; 19: 468-478.
 23. Northouse LL, Katapodi MC, Song L, et al. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin* 2010; 60: 317-339.