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Perceived Stress Levels and Influencing Factors of Stress in Family Caregivers: A Cross-Sectional Study

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ABSTRACT

Objectives: This study aims to measure the perceived stress level of family caregivers of patients in palliative care units, and to reveal the socio-cultural and health-related characteristics that might affect their perceived stress.

Methods: The population of this cross-sectional study consisted of family members who had taken care of their patients who were hospitalized in palliative care units between March 1, 2018, and June 1, 2018. A socio-demographic questionnaire and Perceived Stress Scale-14 (PSS-14) was applied face-to-face to all participants. Moreover, the Patient Health Questionnaire (PHQ-2) was applied to all participants.

Results: Seventy-five family caregivers attended to the study. Twenty-two (34.7%) of family caregivers were patients' children. Fifty-seven (75.0%) of family caregivers struggled with problems during care processes. Fifteen (19.5%) participants gave positive responses to both questions of the PHQ-2. The number of family caregivers who had chronic diseases was 49 (64.5%). The mean score of PSS-14 was 46.9±5.7.

Conclusion: Difficulties in the management of care processes may have increased perceived stress levels and may adversely affect the caregivers' health and social life. Providing early psychological support to family caregivers by health professionals may help to reduce perceived stress.

Keywords: Family caregivers, palliative care, psychologic stress

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INTRODUCTION

Palliative care improves the quality of life of the patients in progressive, terminal fatal diseases.[1] Palliative care, as stated by the World Health Organization, aims to support psychosocial and spiritual problems, to treat patients' physical complaints and, to support family and caregivers. For palliative care, reliable relationships between caregivers, family and social environments are important for patients.[2] If these sources of support are exhausted, palliative care becomes limited.[3] Family members play a very important role in patient care in palliative care. Family caregivers support patients by providing personal care, psychological support, and taking care of medication administration.[4] However, it has been reported that family caregivers do not only have to meet the care needs of their patients, but also have to deal with problems related to their own health, family, and perhaps work situations.[5] Family caregivers may experience anxiety, depression, sleep disturbance, and they feel physically tired and exhausted.[3,6] It has been reported that family caregivers, especially middle-aged, had lower quality of life related to health than the general population.[7] When the caregiver is a member of the family, the caregiver's exposure to stress further affects patient care.[8] Caregivers, who have been exposed to stress for a long periodin various health problems such as family caregivers of palliative patients, suffer loss of various functions and experience decreasing quality of life.[9] Scientific efforts to measure stress that affects human life in many ways, and to develop tools that can be used for this measurement have revealed some scales. One of them is the Perceived Stress Scale (PSS), which is commonly used to address subjective stress perception.[10] To ensure its use in scientific research and applications in our country, reliability, and validity studies were conducted in Turkish.[11]

Palliative care services in Turkey were launched within the home care services, framework of the "Health Transformation Program", by the Ministry of Health in 2010.[12] In the continuation of home care services, legislative regulations were made to establish palliative care units (PCUs) in hospitals. The Turkish Ministry of Health provides palliative care services with 393 health units in 81 provinces.[13] There was a 10-bed PCU in Erzincan Mengücek Gazi Training and Research Hospital in Erzincan during the study period.[14]

The present study aimed to measure the perceived stress level of family caregivers who had taken care of their patients in PCUs, and to reveal the socio-cultural and health-related characteristics that might affect their perceived stress.

METHOD

The population of this observational study consisted of family members who took care of their patients who were hospitalized in the PCU of Erzincan Mengücek Gazi Training and Research Hospital between March 1, 2018, and June 1, 2018. The convenience sample method was used during this period. The inclusion criteria of the study were stated as family caregivers who gave palliative care to their patient for at least two weeks at any time, had no language and/or health problems that may prevent them from expressing their opinions, acceptance and signing of the consent form prepared by the researchers, and were over the age of 18 and below 65 years.

Not responding to all items of applied questionnaires or scale was determined as the exclusion criterion of the study.

A socio-demographic questionnaire, including questions about the patient's socio-cultural and demographic characteristics, health status, and the patient's illness history were applied face to face to the family caregivers by the researchers. In addition, PSS-14 was applied face to face to measure the stress levels of the participants. Further, the Patient Health Questionnaire (PHQ-2) was applied all the participants. PHQ-2, also named as "Short depression screening scale", has two questions and a positive answer for both questions means that the person should be referred for further evaluation for depression.[15]

It was emphasized that the participants should complete answers to the all 14 questions included in the PSS-14. The PSS-14 is a five-point Likert scale with points as "0=never", "1=almost never", "2=sometimes", "3=quite often", "4=very often". Items 4, 5, 6, 7, 9, 10, and 13 of the PSS-14 are the positively stated items, so these items are scored in reverse. PSS-14 scores range from 0 to 56, and higher scores indicate higher perception of stress. The internal consistency of the Cronbach-Alpha coefficient regarding the reliability of the PSS-14 was calculated as 0.84, thus the reliability level of the scale was found sufficient.[11] Moreover, individuals were asked to evaluate whether their chronic diseases were under control or not, on a 10-point scale, and ≥7 points were considered as "under control" and <7 points as "uncontrolled".

The analyzes were performed with the IBM SPSS Statistics 25 program. It was determined that the normality assumption required for these analyzes was provided by both the kurtosis and skewness coefficients, and the normality tests (Kolmogorov-Smirnov test and Shapiro-Wilk test). Frequency, percentage, mean, standard deviation, median, minimum and maximum were used for descriptive statistics of the data. Continuous variables with normal distribution were evaluated with Student t test and one-way ANOVA test, continuous variables without normal distribution were evaluated with Spearman correlation test. In all analysis results, $p<0.05$ was considered significant.

RESULTS

Seventy-five participants were included in the present study and the mean PSS-14 score was 46.9±5.7. The PSS-14 scores according to the socio-demographic and health-related characteristics of the participants are summarized in Table 1.

It was observed that there was a positive and significant relationship between the number of diseases and the stress level ($r=0.210$, $p=0.035$). According to the results, perceived stress scores increase as the number of chronic diseases increases. Moreover, it was revealed that there was a signifi-

Table 1. The PSS-14 scores according to the socio-demographic and health-related characteristics of the participants

	n (%)	PSS-14 score	p
Relationship by affinity			
Wife or child	32 (42.7)	29.3±9.3	0.392*
Others	43 (57.3)	30.9±7.8	
Age groups			
Under 52 years old	34 (45.3)	31.8±8.0	0.124*
≥52 years old	41 (54.7)	28.8±8.7	
Gender			
Women	57 (76.0)	30.9±8.4	0.180*
Men	18 (24.0)	27.9±8.4	
Marital status			
Single	64 (85.3)	29.7±8.1	0.198*
Married	11 (14.7)	33.8±10.3	
Occupation			
No	57 (76.0)	30.9±8.8	0.226*
Yes	18 (24.0)	28.1±7.1	
Educational status‡			
Elementary and middle schools	45 (71.4)	30.1±8.1	0.796*
High school and over	18 (28.6)	29.4±9.6	
Monthly income			
Low	12 (16.0)	29.9±10.3	0.593†
Moderate	48 (64.0)	30.9±7.4	
High	15 (20.0)	28.3±10.2	
Lived together			
Alone	8 (10.7)	33.4±9.4	0.508†
Spouse	28 (37.3)	30.6±7.5	
Spouse and child/children	32 (42.7)	28.7±8.8	
Others (mother and/or father, homemate, etc.)	7 (9.3)	31.7±9.9	
Chronic disease			
No	27 (36.0)	28.4±7.3	0.155*
Yes	48 (64.0)	31.3±8.9	
Number of chronic disease			
No or one chronic disease	48 (64.0)	30.0±8.1	0.738*
≥2 chronic diseases	27 (36.0)	30.7±9.3	
Control status group of chronic disease(s)			
Uncontrolled chronic disease	27 (56.2)	33.7±7.4	0.031*
Controlled chronic disease	21 (43.8)	28.1±9.9	
Use of medication for chronic disease(s)			
No	36 (48.0)	29.5±8.4	0.462*
Yes	39 (52.0)	30.9±8.6	
Number of medications			
One medication	22 (56.4)	31.5±7.7	0.640*
≥2 medications	17 (43.6)	30.2±9.8	
Number of clinics that patient has been hospitalised			
≤2	42 (58.3)	29.4±9.7	0.322*
≥3	30 (41.7)	31.3±6.6	

Table 1. CONT.

	n (%)	PSS-14 score	p
Duration of hospital stay			
Under 90 days	44 (58.7)	29.7±9.7	0.503[*]
≥90 days	28 (37.3)	30.7±6.4	
Patients care out of clinic			
No	16 (21.3)	31.8±8.3	0.402[*]
Yes	59 (78.7)	29.8±8.5	
Duration of care out of the clinic			
≤90 days	21 (35.6)	29.5±8.4	0.832[*]
≥90 days	38 (64.4)	30.0±8.7	
Number of problems encountered in out-of hospital care[§]			
No or one	21 (36.8)	27.6±7.2	0.091[*]
≥2 problems	36 (63.2)	31.2±7.8	
Positive answer for both PHQ-2 questions			
No	60 (80.0)	30.5±9.0	0.556[*]
Yes	15 (20.0)	29.1±6.1	

PHQ-2: Patient health questionnaire-2; PSS-14: Perceived stress scale-14.

[‡] Illiterates were not grouped; [§] Based on what family caregivers state as problems during caregiving.

Data were presented as mean±standard deviation.

[*] Student t-test; [†] One-way ANOVA test.

cantly negative relationship between the status of keeping chronic diseases under control and their stress levels (r=–0.370, p=0.005). Therefore, it can be said that PSS-14 scores were high in family caregivers whose chronic diseases were not under control.

The median number of drugs was 2.0 (1.0-4.0) among 39 (52.0%) family caregivers, who administered medications regularly to their patients. Seventy-two (96.1%) patients were reported hospitalized, and the median duration of hospitalization was 60.0 (3.0-365.0) days. Family caregivers who previously cared for their patients at home or in an out-of-hospital setting was 58 (77.6%), and 57 (75.0%) of these had some problems during their care. The most common problems that family caregivers encountered at home or in out-of-hospital setting summarized in Table 2.

The participants stated that they had not attended a structured palliative care training. The number of family caregivers who responded positively to both questions of the PHQ-2 was 15 (19.5%). Forty-nine (64.5%) of family caregivers had a chronic disease. The frequency of family caregivers' chronic diseases summarized in Table 3.

The median score of the 10-point scale was 4.0 (0.0-10.0), which evaluated whether their chronic diseases were under control or not. Further, 28 (36.8%) of these family caregivers stated that their chronic diseases were not under control at all.

Table 2. The most common problems that family caregivers encountered at home or in out-of-hospital setting

Problems	n (%)
Changing disposable underpad	35 (46.7)
Bathing	20 (26.7)
Changing the positions of patient	15 (20.0)
Feeding	14 (18.7)
Relief of any pain	7 (9.3)
Not to have enough time for doing something (for family caregivers)	7 (9.3)
Giving medication	3 (4.0)
Sleeping problems	2 (2.7)
Financial difficulty	2 (2.7)
Decubitus ulser care	1 (1.3)
Communication	1 (1.3)

DISCUSSION

Most of the caregivers of patients were their children. The number of the patients who had been hospitalized thus far was 96.1% and the median length of hospitalization was 60.0 days. 77.6% of these family members had previously cared for their patients at home or in an out-of-hospital setting, and 75.0% stated that they had problems during their care. The most important problems and difficulties encoun-

Table 3. The frequency of family caregivers' chronic diseases

Chronic Disease	n (%)
Hipertension	28 (36.8)
Diabetes mellitus	17 (22.4)
Thyroid diseases	8 (10.5)
Dyslipidemia	8 (10.5)
Hearth diseases	6 (7.9)
Anxiety disorders	5 (6.6)
Asthma	5 (6.6)
Rheumatological disease	4 (5.3)
Allergic rhintis	3 (3.9)
Epilepsy	2 (2.6)
Cancer	1 (1.3)
COPD	1 (1.3)
Depression	1 (1.3)

COPD: Chronic obstructive pulmonary diseases.

tered were changing disposable underpad and bathing. 19.5% participants gave positive responses to both questions of the PHQ-2. There was a significant relationship between 90 days or more of hospitalization and the positive responses to the PHQ-2, 42.1% family caregivers lived with their spouses and children and, 64.5% family caregivers had a chronic disease. Hypertension and diabetes were the most reported chronic diseases within family caregivers. 36.8% of these family caregivers stated that their chronic diseases were not under control at all. The mean score of the PSS-14 was 46.9.

It was stated that the rate of family caregivers within cancer group patients who needed palliative care was 80% in USA.[16] No information was found in the literature for rate of family caregivers in palliative care patients in Turkey; however, it was stated that 42.6% of family caregivers were children of patients.[17] In our study, 34.6% family caregivers were the children of the palliative care patients. The rate of family caregivers was lower than the USA because relatives such as, an uncle, aunt, uncle, still, aunt were classified as "other relatives" in the present study. It has been stated that family members of caregivers can facilitate clinical and psychosocial practices in health services.[18] Similar to Chinese and Japanese culture, the belief that spouses and children should deal with elderly and sick individuals is a dominant belief in Turkish culture.[9] Therefore, in the present study, it can be said that socio-cultural factors are effective in the role of spouses and children in palliative care services. However, qualitative studies are needed to investigate socio-cultural differences in patient care processes.

In many studies, it has been stated that women were most family caregivers providing care services.[18, 19] In our literature review, it was determined that studies on why women are more in care processes were not sufficient, and national studies were not found.[20] In the present study, the number of female family caregivers dealing with patients undergoing palliative care was 77.3%. Qualitative studies are needed in this regard.

Despite the high rate of family caregivers, they are often unable to manage the care process, and unable to make decision for their patients.[21] As the burden of family caregiver increases, caregivers who are not prepared for care may experience greater outcomes, such as depression and mortality.[9] It was also stated that family caregivers in palliative care were at risk for depression and depressive symptoms.[22] "*Primary caregiver syndrome*" also known as "*stress in primary caregivers*" can be seen in family caregivers of patients undergoing palliative care, which is explained as combination of fatigue, loss of energy, exhaustion and tiredness. Moreover, 96.0% of family caregivers were under stress, and felt sad and exhausted.[23] Despite these data, it was stated that there is not enough literature about the relationship between palliative care services and the emotional state of family caregivers.[18,24] In the present study, 19.5% of the family caregivers gave positive responses to all of the PHQ-2, while 1.3% of the family caregivers were diagnosed with depression. The individuals who give positive responses to all the PHQ-2 should be reached for further evaluation of depression.[15] Even though the positive response of the family members to the PHQ-2 is not sufficient for the diagnosis of depression, it can be said that the rate of depressed patients may be higher than what is known.

Beside many studies that stated that the mean duration of hospitalization for palliative care patients being shorter than 6 months is optimal, a study conducted in the USA stated that the mean period of palliative care hospitalization was 34 days.[25-27] However, in the same study, it was stated that direct comparison of hospitalization time is difficult due to the different characteristics of the PCUs, and the components of the care provided.[27] In the present study, the median duration of hospitalization was 60.0 days. The different lengths of hospitalization in the present study might be caused by factors such as diversity of reason for admission to the PCU, disease history, age, and different expectations from palliative care.

In 2011, it was stated that the prevalence of hypertension was 24.0%, and that of diabetes mellitus was 11% in Turkey.[28] According to the TURDEP-2 study, the prevalences of hypertension and diabetes were 25.6% and 13.7%, respectively.[29] In the present study, 36.8% family caregivers were diagnosed with hypertension and 22.4% of them were diabetics. It can be emphasized that the prevalences of hypertension and diabetes in our study were higher than those of these two studies in Turkey. Moreover, it was stated that stress can lead to various chronic diseases.[30] Therefore, stress might be the cause of high rates of chronic diseases among family caregivers in the present study.

The PSS-14 was used in many different studies, and different averages were reported between 18.5 and 32.6.[31-33] Moreover, a few studies were focused on the stress burden of caregivers within PCUs.[2-4,6,7] Gema at al. stated that 77.0% of the caregivers had probable significant distress, 76.1% had anxiety, and 77.4% had depression which were measured by the Hospital Anxiety and Depression Scale.[34] However, we found only one study that applied the PSS scale for caregivers in PCUs. In the presents study, the PSS mean score was determined as 18.7 in caregivers of Alzheimer's patients.[35] In our literature search, there was no any study that used PSS-14 on family caregivers of patients in PCUs. The mean score of PSS-14 was 46.9 in the present study. It can be stated that the mean score is high in comparison with other studies in the literature. Future studies should investigate the causes of this high perceived score.

The limitations of this study were that the selection of participants was only among the caregivers who were in the PCU during the study period, the histories about the health of the patients were based on only the statements of the caregivers, and there was a lack of qualitative data.

CONCLUSION

In the present study, 34.6% family caregivers were the children of the palliative care patients. Family caregivers stated that they struggled with various problems in the care processes of their patients. These problems in the care process may have increased perceived stress levels and may adversely affect the caregivers' health and social life. Providing early psychological support to family caregivers by health professionals may help to reduce perceived stress. It might be emphasized that organizational arrangements and practices for psychosocial support should be revised in PCUs. Further, qualitative studies and larger descriptive studies on socio-cultural and health factors affecting perceived stress should be carried on in the future.

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