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The effect of care-related attitudes of palliative patients' relatives on stress levels

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Abstract

This study was conducted as a descriptive and relationship-seeking study to determine the effects of care-related attitudes of inpatients' relatives in the palliative care unit on stress levels. The study was carried out with the participation of 160 relatives of patients who were under care and treatment in the palliative care unit and internal and surgical clinics of a training and research hospital. The study group of the study consisted of 80 relatives of patients who were cared for and treated in the palliative care unit; The control group consisted of 80 relatives of patients who continued their care and treatment in internal and surgical clinics. In the study, data were collected using a descriptive information form for the patient and their relatives, the Frommelt Attitude Toward Care of the Dying Scale (FATCOD), and the Caregiver Strain Index (CSI). It was determined that the attitudes and stress levels of the relatives of the patients towards caring for the dying individual were moderate. It was determined that, as the attitudes of the relatives of the patients towards giving care to the person approaching death increased, the scores of the caregivers in the strain index decreased.

Keywords: Care; palliative care; patient; relatives; stress.

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1. Introduction

The world population lives for more and more time due to the advances in health, science, and technology; depending on this situation, the number of patients struggling with cancer and chronic diseases as well as the number of individuals in need of palliative care increases [1-4]. The World Health Organization (WHO) defines palliative care as "the elimination of pain and other symptoms of patients and families with life-threatening diseases from the diagnosis of the disease to death and increasing their quality of life by meeting their psychosocial and spiritual needs as early as possible" [5].

In palliative care, life and death are seen as normal processes. Palliative care is concerned with the quality of life rather than the life span. Palliative care aims to facilitate the transition from life to death. As death approaches, efforts that comfort the patient and family are increased in palliative care [6,7]. In this direction, it is quite important in palliative care services to ensure that the patients and their relatives play an active role in the treatment and care process by evaluating the patients and their relatives together. Patient relatives have many complex tasks such as managing the symptoms of the patients, meeting their self-care needs, finding solutions to their various physical, psychosocial, emotional, and spiritual problems, and making decisions [8,9].

The palliative care process increases the care burden of patient relatives and makes it difficult for them to psychologically adapt to current conditions [10]. With the worsening prognosis of the patient, the patient's relatives have difficulty coping with many stressors; they experience problems such as fatigue, fear, weakness, hopelessness, anxiety, and depression. Both the quality of life of the patient's relatives and the quality of care received by the patients are affected by these factors [8, 11-15].

Knowledge and attitudes of palliative patient relatives about care help to reduce the fears and anxieties of patients approaching death, to comfort the physical symptoms of patients, and give them a respectable death in a peaceful and safe environment in the last stage of their life [16-18]. Determination of the attitudes of palliative patient relatives about giving care to patients approaching death and the factors affecting these attitudes may help to increase the quality of care provided to the patients and reduce the stress, anxiety, feelings of incompetency, depression, and exhaustion in palliative patient relatives [19,20].

1.1. Purpose of the study

This study was conducted to determine the effect of the attitudes of relatives of patients hospitalized in the palliative care unit regarding care on their stress levels. Answers to the questions below were sought in this study:

- What are the sociodemographic characteristics of relatives of patients hospitalized in the palliative care unit?
- What are the attitudes of relatives of patients hospitalized in the palliative care unit about care?
- At what level is the stress of relatives of patients hospitalized in the palliative care unit?
- Is there any relationship between the attitudes of relatives of patients hospitalized in the palliative care unit about care and their stress level?

2. Materials and methods

2.1. Participants

Planned as descriptive, cross-sectional, and relationship-seeking, this study was conducted with the participation of the relatives of patients undergoing care and treatment in the palliative care unit and internal and surgical clinics of a hospital located in the Central Black Sea Region in the north of Turkey. The study was conducted with the participation of 160 relatives of patients who were receiving care and treatment in palliative, internal, and surgical clinics at the time of the study, determined by the improbable sampling method. The study group of the study consisted of 80 relatives

of patients receiving care and treatment in a palliative care unit, and the control group consisted of 80 relatives of patients receiving care and treatment in internal and surgical clinics. Patient relatives aged 18 years and over, with a minimum level of literate education, male or female, who can communicate verbally, who are primarily responsible for the patient's care, and who are willing to participate in the study were included in the study.

2.2. Data collection tools

The data were collected in the study by using the patient and patient relative introductory information form, the Frommelt Attitude Toward Care of the Dying Scale (FATCOD), and the Caregiver's Stress Index. The questionnaire form consists of 22 questions that include sociodemographic and clinical characteristics of patients; sociodemographic and caregiving characteristics of patient relatives. The questionnaire form was pre-applied and tested in a group of 10 people included in the pilot study, and the relatives of patients participating in the pilot study were not included in the sample. It was explained to the patient's relatives within the scope of the study that the data obtained from the study will only be used within the scope of the study, and the decision on whether to be included in the study is entirely their own, and their verbal informed consent was obtained.

2.2.1. Frommelt Attitude Toward the Care of the Dying scale (FATCOD)

To measure the attitude toward caring for a dying person, Frommelt developed the Frommelt Attitude Toward Care of the Dying Scale (FATCOD) in 1988. The validity and reliability tests of the scale in Turkish were conducted by Cevik and Kav [21]. The scale is a five-point Likert-type scale consisting of 30 items. The scale contains an equal number of statements containing positive and negative attitudes 1 is scored as completely disagree and 5 as completely agree. The total score of the scale is obtained by summing the items containing negative attitudes (3, 5, 6, 7, 8, 9, 11, 13, 14, 15, 17, 19, 26, 28, 29) together with positive answers by reversing them. The total score that can be obtained from the scale varies between 30 and 150 and high scores indicate a more positive attitude. Cronbach's Alpha reliability coefficient of the scale was determined as 0.69 in the validity and reliability analyses made by Cevik and Kav [21]. In this study, the Cronbach's Alpha reliability coefficient of the scale was 0.92 in the control group and 0.89 in the study group.

2.2.2. Caregiver Strain Index (CSI)

The Caregiver's Strain Index was developed by Robinson [22] to measure the caregiver's burden of care. Its validity and reliability analysis in Turkish was made by Ugur [23]. The scoring of the scale, which consists of 13 items, ranges from 0-1. While the total score that can be obtained from the scale varies between 0-13, a score above 7 subjectively indicates the burden of care. In his validity and reliability analyses, Ugur [23] determined Cronbach's Alpha reliability coefficient of the scale as 0.77 in the first application and 0.73 in the second application. In this study, Cronbach's Alpha reliability coefficient of the scale was determined as 0.94 in the control group and 0.89 in the study group.

2.3. Ethics and Data collection

The data were collected by the researchers through face-to-face interview techniques with the patient's relatives. After informing the patient relatives included in the study about the study, the questionnaire form and scales were applied. It was explained to the patient relatives that the decision to participate in the study is entirely their own, their names will not be written on the questionnaire, and the data obtained from the study will only be used as part of the study. The data collection process took approximately 20 minutes.

2.4. Data analysis

Statistical analysis of the data belonging to the patient relatives included in the study was analyzed using the SPSS 21.0 package program in a computer environment. The normality of the data was determined by the Kolmogorov-Smirnov test. The Kruskal-Wallis's test and the Mann-Whitney U test were used to analyze the data that did not show a normal distribution. The results were presented

as frequency, percentage, median, minimum, and maximum. The relationship between the scales was examined with Spearman correlation analysis. The level of significance was taken as $p < 0.05$.

3. Results

Sociodemographic and clinical features of patients who were taken care of by their relatives in the study and control groups are given in Table 1. It was determined that 51.3% of the patients were female and 48.8% were male, 26.9% graduated from high school and 27.5% graduated from primary school, 65% were married, 51.9% were living together with their spouse and children, 30.6% were diagnosed with cancer, 23.1% with renal insufficiency and 10% with neurological diseases and respiratory diseases, 75.6% had a chronic disease, 34.1% had hypertension and 26.7% had diabetes (Table I).

TABLE I

SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF THE PATIENTS IN THE STUDY AND CONTROL GROUP

Demographic and clinical characteristics	Control		Study		Total			
	n	%	n	%	n	%		
Age	20-45age	13	16.2	11	13.8	24	15.0	
	46-70age	36	45.0	31	38.8	67	41.9	
	71 and older	31	38.8	38	47.4	69	43.1	
Gender	Female	45	56.3	37	46.2	82	51.3	
	Male	35	43.7	43	53.7	78	48.7	
Education status	illiterate	13	16.3	11	13.8	24	15.0	
	Literate	7	8.8	15	18.8	22	13.8	
	Primary school	35	43.6	9	11.0	44	27.3	
	Secondary school	5	6.3	11	13.8	16	10.0	
	High school	16	20.0	27	33.8	43	26.9	
	University	4	5.0	7	8.8	11	6.9	
Marital status	Married	54	67.5	50	62.5	104	65.0	
	Single	26	32.5	30	37.5	56	35.0	
Who does the patient live with?	partner	11	13.8	20	25.0	31	19.3	
	their children	15	18.8	17	21.3	32	20.0	
	wife and children	38	47.5	29	36.1	67	41.9	
	alone	13	16.1	11	13.8	24	15.0	
	relatives	3	3.8	3	3.8	6	3.8	
Diagnosis of the patient	cancer	1	1.3	48	60.0	49	30.6	
	Road System Diseases	14	17.5	2	2.5	16	10.0	
	diabetes	9	11.3	-	-	9	5.6	
	Neurological Disorders	11	13.8	5	6.1	16	10.0	
	Cardiac Disorders	6	7.5	2	2.5	8	5.0	
	Psychiatric Disorders	4	5.0	11	13.8	15	9.4	
	Gastrointestinal System Disorders	1	1.1	9	11.3	10	6.3	
	Renal System Disorders	34	42.5	3	3.8	37	23.1	
	When did she/he get the diagnosis	0-6 month	21	26.1	13	16.3	34	21.3
		7-13 month	14	17.5	15	18.8	29	18.1
14-19 month		7	8.8	24	30.0	31	19.4	

	20-25month	9	11.3	12	15.0	21	13.0
	26-31 month	5	6.3	5	6.1	10	6.3
	32 and above	24	30.0	11	13.8	35	21.9
Having any chronic disease	Yes	66	82.5	55	68.8	121	75.6
	No	14	17.5	25	31.2	39	24.4
*If the answer is yes, what are these disease(s)?	heart disease	24	14.0	9	10.3	33	12.8
	diabetes	49	28.7	20	23.0	69	26.7
	hypertension	58	33.9	30	34.5	88	34.1
	atherosclerosis	10	5.8	3	3.4	13	5.0
	Kidney failure	7	4.1	4	4.6	11	4.3
	Asthma	11	6.4	11	12.6	22	8.5
	chronic obstructive pulmonary disease	9	5.3	10	11.5	19	7.4
	other	3	1.8	-	-	3	1.2

It was determined that 68.8% of the study group patient relatives who participated in the study were female and 31.3% were male, 62.5% were married, 21.8% graduated from high school, 47.5% did not work, 31.3% were housewives, 88.8% had a nuclear family structure, 53.8% were living together with their patient, 81.3% had no chronic diseases, 32.1% were diagnosed with diabetes and 10.7% with hypertension, 26.3% had been taking care of their patient for 0-3 months, 61.3% encountered the death of other patients during the period of their accompaniment in palliative care, 31.3% cried and were very sad when they encountered death, 75% had difficulties when taking care of their patient, 52.2% were sad when taking care of their dying patient (Table II).

It was determined that 76.3% of the control group patient relatives who participated in the study were female and 23.7% were male, 81.3% were married, 21.3% graduated from high school, 58.8% did not work, 43.8% were housewives, 82.5% had a nuclear family structure, 61.3% were living together with their patient, 51.3% had no chronic diseases, 35.2% were diagnosed with diabetes and 48.1% with hypertension, 25% had been taking care of their patient for 0-3 months, 38.8% encountered the death of other patients during the period of their accompaniment in palliative care, 29.8% cried and were afraid and very sad when they encountered death, 58.8% had difficulties when taking care of their patient, 52.2% were sad when taking care of their dying patient (Table II).

TABLE II

SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF STUDY AND CONTROL GROUP PATIENT RELATIVES

Characteristics	Control		Study		Total		
	n	%	n	%	n	%	
Age	18-35age	13	16.2	27	33.8	40	25.0
	36-53age	41	51.3	41	51.2	82	51.2
	53and older	26	32.5	12	15.0	38	23.8
Gender	Female	61	76.3	55	68.8	116	72.5
	Male	19	23.7	25	31.2	44	27.5
Marital status	Single	12	15.0	23	28.7	35	21.9
	Married	65	81.2	50	62.5	115	71.9
	Divorced/widowed	3	3.8	7	8.8	10	6.2
Educational status	Literate	10	12.6	9	1.3	14	8.2
	Primary school	30	37.5	9	11.3	35	21.9
	Middle School	12	15.0	43	53.8	21	13.0
	High school	17	21.1	19	22.6	60	37.5
	University	11	13.8	80	1.0	30	18.8
Working status	Yes	33	41.2	42	52.5	75	46.9
	No	47	58.8	38	47.5	85	53.1
Occupation	Housewife	35	43.8	25	31.3	60	37.5

	Employee	16	20.0	15	18.8	31	19.3
	Officer	12	15.0	12	15.0	24	15.0
	Self-employment	2	2.5	17	21.1	19	11.9
	Retired	9	11.2	2	2.5	11	6.9
	Student	2	2.5	7	8.8	9	5.6
	Unemployed	4	5.0	2	2.5	6	3.8
Patient's relative social security	there is	74	92.5	59	73.8	133	83.1
	none	6	7.5	21	26.2	27	16.9
Place of residence of the patient's relative	province	40	50.0	43	53.8	83	51.9
	District	34	42.5	37	46.2	71	44.3
	village	6	7.5	0	0	6	3.8
The family structure of the patient's relative	Nuclear family	66	82.5	71	88.8	137	85.6
	Extended family	14	17.5	9	11.2	23	14.4
Status of having a child relative to the patient	Yes	63	78.8	52	65.0	115	71.9
	No	17	21.2	28	35.0	45	28.1
Income status of the patient's relative	Income less than expenses	17	21.3	29	36.3	46	28.8
	Income equals expense	46	57.5	46	57.5	92	57.5
	Income more than expenses	17	21.2	5	6.2	22	13.7
Degree of intimacy with the patient	Partner	18	22.5	18	22.5	36	22.5
	mother/father	43	53.8	33	41.3	76	47.5
	Brother	3	3.8	2	2.5	5	3.1
	child	8	10.0	1	1.3	9	5.6
	Other	8	10.0	26	32.5	34	21.3
Living in the same house as the patient	Yes	49	61.2	43	53.8	92	57.5
	No	31	38.8	37	46.2	68	42.5
The state of being an accommodation environment in the proximity of the patient	Yes	39	48.8	15	18.8	54	33.8
	No	41	51.2	65	81.2	106	66.2
* If the answer is yes, what are these disease(s)?	Heart disease	6	11.1	4	14.3	10	12.2
	diabetes disease	19	35.2	9	32.2	28	34.1
	hypertension	26	48.0	3	10.7	29	35.4
	atherosclerosis	-	-	1	3.6	1	1.2
	Kidney failure	1	1.9	1	3.6	2	2.4
	Asthma	-	-	6	21.4	6	7.3
	chronic obstructive pulmonary disease	1	1.9	2	7.1	3	3.7
	other	1	1.9	2	7.1	3	3.7
Patient care time	0-3 month	20	25.0	21	26.2	41	25.6
	3-6 month	10	12.5	16	20.0	26	16.3
	6-9 month	14	17.5	18	22.5	32	20.0
	9-12 month	9	11.2	11	13.8	20	12.5
	Bir yıldan fazla	27	33.8	14	17.5	41	25.6
Is palliative care only given to cancer patients?	Yes	56	70.0	32	40.0	88	55.0
	No	24	30.0	48	60.0	72	45.0
Is palliative care a treatment applied to prolong life?	Yes	48	60.0	46	57.5	94	58.8
	No	32	40.0	34	42.5	66	41.2
The situation of encountering the phenomenon of death in the accompanying process	Yes	31	38.8	49	61.3	80	50.0
	No	49	61.2	31	38.8	80	50.0
*If the answer is yes, the first emotion/feeling felt when faced with the phenomenon of death.	feeling nothing	4	8.5	1	1.5	5	4.4
	Do not be afraid	14	29.8	16	23.9	30	26.3
	crying and sad	14	29.8	21	31.3	35	30.7
	natural welcome	5	10.6	9	13.4	14	12.4
	Don't think your pain is over and you're saved	10	21.3	19	28.4	29	25.5

Difficulty in caring for the patient	Yes	47	58.8	60	75.0	107	66.9
	No	33	41.3	20	25.0	53	33.1
Emotions/feelings experienced while caring for her dying patient	Anger	7	4.3	2	1.7	9	3.2
	sorrow	32	19.8	26	22.6	58	20.9
	Sadness	64	39.5	60	52.2	124	44.8
	Guilt	5	3.1	6	5.2	11	4.0
	Fear	37	22.8	16	13.9	53	19.1
	cry	17	10.5	3	2.6	20	7.2
	other	-	-	2	1.7	2	.7

The comparison of the study and control group patients' relatives in terms of the Frommelt Attitude Toward Care of the Dying Scale and Caregiver's Strain Index scores between the groups is presented in Table 3. It was found that there was a statistically significant difference between the total median scores of the study and control group patients' relatives on the Frommelt Attitude Toward Care of the Dying Scale. It was determined that the total median score of the Frommelt Attitude Toward Care of the Dying Scale was higher in patient relatives who received care and treatment in a palliative clinic (Table III).

TABLE III

COMPARISON OF FROMMELT ATTITUDE TOWARD THE CARE OF THE DYING SCALE AND CAREGIVER STRAIN INDEX OF STUDY AND CONTROL GROUP PATIENTS' RELATIVES

	Control group	Study group	Test value	p-value
Caregiver Strain Index	9(0-13)	7.5 (0-13)	U= 2766.00	0.137
Frommelt Attitude Toward the Care Of the Dying Scale	96.50(85-115)	101(87-130)	U= 2377.00	0.005

U: Mann Whitney U Test statistics.

The relationship between the Frommelt Attitude Toward Care of the Dying Scale and the Caregiver Strain Index is presented in Table IV. It was determined that there was a moderately significant negative correlation between the Frommelt Attitude Toward Care of the Dying Scale and the Caregiver's Strain Index. It was determined that as the Frommelt Attitude Toward Care of the Dying Scale score increased, the Caregiver Strain Index score decreased ($p < 0.001$). In line with the findings obtained, it was determined that the stress rate experienced by people who scored high on the Frommelt Attitude Toward Care of the Dying Scale was lower.

TABLE IV

THE RELATIONSHIP BETWEEN THE FROMMELT ATTITUDE TOWARD THE CARE OF THE DYING SCALE AND CAREGIVER STRAIN INDEX

	Caregiver Strain Index
Frommelt Attitude Toward Care Of the Dying Scale	-0,349

Note. Spearman's correlation coefficient. * $p < .001$

4. Discussion

In this study, which was conducted to determine the effect of attitudes of the relatives of patients in a palliative care unit of a hospital in the Central Black Sea Region about care on stress levels, the findings obtained were discussed by the relevant literature. In this study, it was determined that there was a statistically significant difference between the study and the control group in terms of median scores on the Frommelt Attitude Toward Care of the Dying Scale. It was found that the attitudes of the patient's relatives in the study group regarding the provision of care were better than those in the control group. In the study of Karadag and Inkaya [24], in which they examined the attitudes of nursing intern students regarding the care of a dying patient, it was found that the mean total score of the participants in the Frommelt Attitude Toward Care of the Dying Scale was

81.59±12.99. In another study conducted by Aslan et al. [25], the FATCOD score average was determined as 95.2 ±14.1. In a study conducted by Leombruni and his colleagues [26] on nursing students in Italy, the FATCOD total score average was found to be 115.20±7.86. In other studies conducted on this subject, it was determined that the total score obtained from the scale ranged from 77 to 129 [21,27-30].

In this study, the median score of the Caregiver's Strain Index was found to be 9(0-13) in the control group of patient relatives ($p>0.05$). The total score average of the Caregiver's Strain Index was determined as 7.2±3.3 in the study by Yildiz et al. [8] In a study conducted by Gok Ugur and Catiker [31] on caregivers of home care patients, the average score of the Caregiver's Strain Index was found to be 5.12±3.35. In the study conducted by Cetinkaya [32] on individuals who provide care to patients who have had hip or knee replacement surgery in the clinic, the Caregiver's Strain index score average was determined as 4.51±2.74. In their study conducted with the participation of relatives of palliative patients, Bilgehan and Inkaya [33] found the total score of the Caregiver's Strain Index to be 8.94 ± 2.03. In our study, the fact that relatives of palliative patients in the study group scored lower in the Caregiver's Strain Index may be caused by reducing their burden of care by being supported by their families.

In this study, which was conducted to determine the effect of attitudes of the relatives of patients in the palliative care unit about care on stress levels, it can be said that the attitudes of palliative patient relatives about providing care are moderate. Since caregivers are decision-makers, communication providers, advocates, and care providers of their patients, they play important roles in the patient's care and treatment process [34]. In order to properly care for patients hospitalized in the palliative care unit, the caregiver-patient relatives must be directly observed and informed by the nurses [33].

Determining the attitudes of primary care providers toward providing care to patients hospitalized in the palliative care unit and the factors affecting them can help plan initiatives to reduce the stress levels of caregivers. Caregivers can be informed after determining the areas where they have difficulty and by their requirements. At the same time, psychological support can be offered to the palliative patient's relatives [35]. Nurses must consider the physiological and psychological state of the palliative care patient, their care requirements, the personal characteristics of the caregiver, their skills, and the burden of care. They should plan, apply and evaluate nursing care in line with a holistic nursing approach [36,8].

5. Conclusion

It was determined that the attitudes and stress levels of the relatives of the patients towards caring for the dying individual were moderate. It was determined that as the attitudes of the relatives of the patients towards giving care to the person approaching death increased, the scores of the caregivers in the strain index decreased. However, it was observed that the FATCOD scores of the relatives of the patients in the study group were higher than the scores of their lives of the patients in the control group.

It was determined in this study that there was a significant moderate relationship between the Frommelt Attitude Toward Care of the Dying Scale and the Caregiver's Strain Index in a negative way. It was observed that as the Frommelt Attitude Toward Care of the Dying Scale score increased, the Caregiver's Strain Index score decreased. By the findings obtained from the study;

- It is recommended that the problems experienced by the patient's relatives, especially stress, be determined and evaluated at periodic intervals,
- and that initiative is planned and implemented to improve the quality of the patient's relatives' attitudes towards care and reduce their stress levels.

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