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THE RELATIONSHIP BETWEEN SPIRITUAL ORIENTATION AND CARE BURDEN IN RELATIVES OF PATIENTS RECEIVING CHEMOTHERAPY

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ABSTRACT

One of the most used methods in cancer treatment is chemotherapy. Due to the intense effects of this treatment on the physical and emotional states of patients, patients encounter many problems. It is stated that the caregivers' burden of care increases during this treatment process and it is claimed that the spiritual orientation of the caregivers in coping increases. This study aimed to examine the relationship between spiritual orientation and care burden in relatives of patients receiving chemotherapy. This cross-sectional study was carried out with 131 relatives of patients who received chemotherapy in the chemotherapy unit of a university hospital in western Turkey. As a result of this study, it was determined that the relatives of the patients who received chemotherapy had a quite high level of spiritual orientation and that the majority of them had a low level of care burden; however, no relationship was determined between their spiritual orientation and care burden. In line with these results, nurses are recommended to consider the needs of individuals who give care to cancer patients receiving chemotherapy.

Key words: Cancer, Care Burden, Chemotherapy, Nursing Care, Spirituality

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INTRODUCTION

Cancer is an important health problem that has increasingly become widespread with the increasing number of cases and affects the entire society due to the disabilities and deaths it causes. Today, the number of individuals with cancer increases in line with the developments in cancer diagnosis and treatment methods whereas survival time is prolonged (Mystakidou et al., 2007). Despite the prolongation of survival times, treatment-related effects affect the quality of life of patients negatively (Bee et al., 2009).

One of the most used methods in cancer treatment is chemotherapy. Chemotherapy is mostly given in outpatient chemotherapy units. Due to the intense effects of this treatment on the physical and emotional states of patients, patients encounter many problems. These emerging problems affect patients' families and caregivers. Therefore, caregivers of patients receiving chemotherapy constitute a special group (Bee et al., 2009; Sert, 2015). Caregiving is an action that provides many personal satisfactions, increases intimacy and love, contributes to the personal development of individuals, and provides

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positive effects such as self-respect, finding meaning with the experience of care but it has many difficulties as well (Cora et al., 2012; Sert, 2015; Stolz-Baskett et al., 2021; Toseland et al., 2011).

The care-giving/-receiving relationship turns into a one-sided, intense, and long-term dependence that causes problems in the life of the patient's relatives; a conflict occurs between the family roles, work and leisure life, social life of caregivers and caregiving roles, affecting the quality of life of individuals negatively (Nayak et al., 2014). Caregivers may also suffer from their caregiver roles, such as involuntary weight changes, sleep deprivation, depressive symptoms, anxiety, social isolation, and increased death risk (Li et al., 2022).

Besides all these, previous studies stated that the care burden of caregivers of individuals receiving chemotherapy increases during treatment (Küçükoğlu, 2019; Özdemir, 2018; Özdemir et al., 2017; Palos et al., 2011; Şahin et al., 2009). Caregivers have many different coping methods in this challenging process (Fitch, 2020; Serçekuş et al., 2014). Spirituality and religion are important coping strategies for family members who give care to cancer patients (Doumit et al., 2019; Gall & Bladeu, 2017; Hill et al., 2000; 2013; Leyva et al., 2014; Sterba et al., 2014). Spirituality is defined as a force that moves and motivates individuals to find meaning and goals in life (Stanard et al., 2000). Spirituality is a coping strategy that can help alleviate the negative aspects of negative life events. It was reported that spirituality is the most effective coping mechanism following emotional support (Meyerowitz et al., 2000).

Religious and spiritual orientations may also cause patient relatives to perceive this support as a comforting situation for them. In particular, factors such as cultural differences or the degree of closeness of the caregiver may cause caregivers to perceive caregiving as a duty. It can be suggested that people with high spiritual orientation perceive caregiving as a duty and fulfil it believing that it is good for their own mental health. For this reason, these people can be more effective in the caregiving process. On the other hand, no study has shown that individuals with no religious beliefs or with low spiritual orientation exhibit different behaviour in giving care to their patients.

In light of this information, the effects of spiritual orientations on the care burden perceived by caregivers need to be discussed. Revealing the factors that may be associated with the care burden and spiritual orientation of the relatives of patients receiving chemotherapy can be a guide in solving caregivers' problems. Furthermore, this can facilitate the need for support of the spirituality of patient relatives and the work to be done to reduce the care burden. In this context, this study aimed to examine the relationship between spiritual orientation and care burden in the relatives of patients receiving chemotherapy.

Research questions:

- What is the spiritual orientation of the relatives of patients receiving chemotherapy?
- What is the care burden of the relatives of patients receiving chemotherapy?
- Is there a relationship between spiritual orientation and care burden in the relatives of patients receiving chemotherapy?

MATERIAL AND METHODS

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Study Design and Ethical Statement

This analytical-cross-sectional study was conducted to examine the relationship between spiritual orientation and care burden in the relatives of patients receiving chemotherapy.

This study was approved by Aydın Adnan Menderes University Nursing Faculty Non-Invasive Clinical Research Ethics Committee (Ethics committee no: E-76261397-050.99-133536, 05.02.2022). Written institutional permission was taken from the hospital where the study was conducted. Participants were informed about the study and its purpose and their verbal consent was taken. This study was carried out based on the principles of the Declaration of Helsinki.

Population and Sample

This study was carried out with the relatives of patients receiving chemotherapy in the chemotherapy unit of a university hospital in western Turkey between March and June 2022. The sample size of the study was calculated based on the thesis study, titled "Unmet Needs, Care Burden, Anxiety, Depression Levels of Caregivers That Give Care to Patients Who Take Chemotherapy" published by Küçükoğlu in 2019 (n=120) (Küçükoğlu,

2019).. The minimum size of the sample was calculated as at least 110 individuals based on the mean scores on the scales used in the study, with a power of 90%, a Type I error of 0.05, and an effect size of 2.607. The study was completed with 131 patients considering a data loss of 10% (Karasar, 2008). The sample selection was made by random sampling from the caregivers accompanying their patients for chemotherapy.

Inclusion Criteria

- Relatives of patients who were aged 18 or over.
- Whose relatives received chemotherapy.
- Who were primarily responsible for the care of the patient.

Exclusion Criteria

- Those who gave care for a fee.

Data Collection Tools

In the study, a "Questionnaire", the "Spiritual Orientation Scale (SOS)" and the "Zarit Burden Interview (ZBI)" were for data collection.

Questionnaire: This form consists of questions regarding introductory information about patients and their relatives and patients' disease.

Spiritual orientation scale (SOS): The Spiritual Orientation Scale, which was developed by Kasapoğlu (2015), is a 7-point Likert-type scale consisting of 16 items ranked between 1=strongly disagree and 7=strongly agree. The scale consists of 16 items in total. The Cronbach Alpha coefficient of the scale is 0.87. The items of SOS are scored positively and a score of 16-112 can be obtained. A high score on the scale indicates a high level of spiritual orientation (Kasapoğlu, 2015). In this study, the Cronbach Alpha coefficient of the scale was found as 0.96.

Zarit Burden Interview (ZBI): This scale is used to evaluate the care burden perceived by relatives of patients receiving chemotherapy. The scale was developed by Zarit, Reever, and BachPeterson in 1980 (Zarit et al., 1980). Its Turkish adaptation and validity-reliability study were performed by İnci and Erdem (2006). The internal consistency coefficient of the scale was 0.95; the item-total correlation coefficients had moderate, strong, and very strong values (0.43-0.85); the test-retest invariance coefficient was 0.90.

The scale consists of 22 statements that determine the effect of caregiving on the life of the individual. The scale has a Likert-type rating scale from 0 to 4 as never, rarely, sometimes, often, or almost always. The minimum score obtainable from the scale is 0 and the maximum score is 88. The care burden increases as the scale score increases. A score of 0-20 indicates "no care burden"; a score of 21-40 indicates "light care burden"; a score of 41-60 indicates "moderate care burden"; and a score of 61-88 indicates "heavy care burden" (İnci & Erdem, 2016). In this study, the Cronbach Alpha coefficient of the scale was found to be 0.88.

Statistical Analysis

In the study, the data were analyzed in the Statistical Package for the Social Sciences (SPSS) for Windows 22 package program. In data evaluation, according to the results of the normality test (Kolmogorov-Smirnov test), it was determined that the data showed normal distribution (Kurtosis and Skewness between − 1.5 and + 1.5). All descriptive statistics were presented as numbers, percentages, and means. The independent samples t-test, one-way analysis of variance (ANOVA) and correlation analysis, and Tukey test were used to evaluate the data. The results were evaluated at a confidence interval of 95% and a significance level of $p<0.05$.

RESULTS

The mean age of the participants was 42.46±12.85 and 56.5% of them were female. Of the patient relatives, 49.6% had been giving care to their relatives for 1-6 months; 14.5% for 7-12 months; 13.7% for 13-24 months; 22.1% for more than 2 years. Of the patients, 65.6% were independent in their daily work; 28.2% were semi-dependent; 6.1% were dependent. The relatives of the patients helped the patients with hospital work (86.3%), drug supply (65.6%), housework (55.7%), nutrition (36.6%), and individual care (31.3%). 35.9% of the patient relatives provided financial support to their relatives during this process. 67.9% of the patients needed individual care after chemotherapy.

Complications experienced by patients after chemotherapy were nausea (53.4%), vomiting (32.8%), loss of appetite (59.5%), diarrhea (19.1%), anemia (14.5%), constipation (34.4%), mouth sores (19.1%), hair loss (61.8%), fatigue (67.2%), change in skin color (20.6%), pruritus (20.6%) and infection (4.6%). While giving care, the relatives of the patients had the most difficulty in providing psychological support to their patients (44.3%), transportation to the hospital (36.6%), and management of chemotherapy-related problems (35.9%). In addition, 22.1% of the patient relatives also had another relative to whom they were obliged to give care to.

The mean age of the patients receiving chemotherapy was 61.09±12.12 and 61.1% of them were female. The thirty-two point seven percent of the patients

received chemotherapy due to breast cancer; 25.3% due to lung cancer; 8.4% due to colon cancer; 7.5% due to ovarian cancer; 5.3% due to bladder cancer; 6.9% due to pancreatic cancer; 5.4% due to uterine cancer; 2.3% due to gastric cancer; 2.3% due to kidney cancer; 2.3% due to prostate cancer; 1.6% due to liver cancer. The patients received chemotherapy for 1-6 months (47.3%), 7-12 months (24.4%), 13-24 months (12.2%), 2-4 years (6.1%), and more than 4 years (9.9%).

The mean spiritual orientation score of the participants was 93.22±21.18 and the mean care burden score was 26.47±14.26. According to the Zarit Burden interview, 38.2% of the patient relatives did not have a care burden; 47.3% had a light care burden; 10.7% had a moderate care burden; 3.1% had a heavy care burden. When the relationship between spiritual orientation and the care burden of the participants was examined, no statistically significant relationship was determined ($r= 0.036$, $p=0.686$).

The distribution of spiritual orientation and care burden scores of the patient relatives according to the demographic variables is presented in Table 1. Education level, income level, family structure, and any disease of the participants affected their care burden ($p<0.05$). The care burden was significantly higher in those who were illiterate compared to those who received high school education, in those who perceived their income as low compared to those who perceived their income as normal, and in those who had a large family structure and those with any disease ($p<0.05$).

Table 1: Demographic information of caregivers

Variables	n	%
Age		
18-31	30	22.9
32-45	44	33.6
46-59	45	34.4
60-73	12	9.2
Gender		
Female	74	56.5
Male	57	43.5
Marital status		
Married	92	70.2
Single	39	29.8
Education level		
Illiterate	3	2.3
Primary school	37	28.2
Secondary school	18	13.7
High school	32	24.4
Undergraduate and graduate	41	31.3
Employment status		
Yes	50	38.2
No	81	61.8
Occupation		
Housewife	53	40.5
Self-employed	41	31.3
Government official	31	23.7
Student	6	4.6
Income level		
Income<expenses	56	42.7
Income=expenses	61	46.6
Income>expenses	14	10.7
Family structure		
Nuclear family	112	85.5
Large family	19	14.5
Place of residence		
Village-burgh	25	19.1
District	70	53.4
City	36	27.5
Degree of relationship with the patient		
Spouse	39	29.8
Children	6	4.6
Mother-father	70	53.4
Sibling-relative-friend	16	12.2
Living with the patient		
Yes	85	64.9
No	46	35.1
Presence of others who are given care		
Yes	29	22.1
No	102	77.9
Presence of any disease		
Yes	26	19.8
No	105	80.2

DISCUSSION

In this study, which aimed to examine the relationship between spiritual orientation and care burden in the relatives of patients receiving chemotherapy, it was determined that the patient relatives had a very high level of spiritual orientation and that the majority of them had a light care burden. However, no relationship was determined between their spiritual orientation and care burden.

The pain suffered by a loved one during cancer and the treatment process as well as the burden of giving care to that person strain caregivers a lot (Terakye, 2011). Caregivers have many different coping methods in this difficult process (Fitch, 2020; Serçekuş et al., 2014). Spirituality and religion are important coping strategies of family members who give care to cancer patients (Doumit et al., 2019; Leyva et al., 2014; Sterba et al., 2014). Previous studies revealed that caregivers often resort to different positive and negative religious/spiritual coping methods, such as worship, strong belief in God, establishing spiritual relationships with other individuals in the same situation, and considering disease a test/ punishment (Delgado-Guay et al., 2013; Doumit et al., 2019; Serçekuş et al., 2014). In their study, Delgado-Guay et al. (2013) reported that spirituality and religiousness help patients of caregivers cope with cancer and positively affect their patients' physical and emotional symptoms.

Table 2: Comparison between the demographic variables of the participants and their spiritual orientation and spiritual care burden scores

	Spiritual orientation	**Care burden**
Variables	**X ±SD**	**X ±SD**
Age		
18-31	88.50±21.89	24.66±15.36
32-45	91.06±22.48	25.81±11.20
46-59	97.84±19.54	27.00±16.59
60-73	95.66±18.99	31.41±11.95
[a]**Statistic/*p***	*F=1.43 p=0.237*	*F=0.687 p=0.562*
Gender		
Female	95.26±20.30	22.27±14.12
Male	90.60±22.16	25.53±14.51
[b]**Statistic/*p***	*t=1.251 p= 0.213*	*t=0.670 p=0.504*
Marital status		
Married	94.38±20.51	26.04±14.29
Single	90.51±22.71	27.49±14.13
[b]**Statistic/*p***	*t=0.955 p=0.341*	*t=-0.527 p=0.599*
Education level		
Illiterate	103.33±5.85	47.00±11.26
Primary school	97.95±18.52	28.11±14.09
Secondary school	92.28±21.90	31.06±16.18
High school	91.25±24.14	22.38±11.57
Undergraduate and graduate	90.20±21.23	24.73±14.16
[a]**Statistic/*p***	*F=0.916 p=0.457*	*F=3.147* ***p=0.017***
Employment status		
Yes	90.00±23.80	24.58±12.11
No	95.22±19.27	27.66±15.40
[b]**Statistic/*p***	*t=-1.376 p=0.171*	*t=-1.201 p=0.232*
Occupation		
Housewife	99.37±16.57	26.69±15.42
Self-employed	89.36±23.18	27.50±14.12
Government official	88.61±24.02	26.41±13.14
Student	89.16±19.22	18.00±9.12
[a]**Statistic/*p***	*F=2.600 p=0.06*	*F=0.776 p=0.510*
Income level		
Income<expenses	95.86±21.31	30.09±15.86
Income=expenses	91.30±20.09	23.72±13.14
Income>expenses	91.14±25.44	24.29±8.9
[a]**Statistic/*p***	*F=0.75 p=0.474*	*F=3.17* ***p=0.045***
Family structure		
Nuclear family	93.38±21.35	25.16±14.00
Large family	92.32±20.69	34.16±13.63
[b]**Statistic/*p***	*t=0.202 p=0.840*	*t=-2.596* ***p=0.011***
Place of residence		
Village-burgh	90.24±23.02	28.96±18.07
District	92.70±22.20	27.38±13.44
City	96.33±17.72	23.03±12.50
[a]**Statistic/*p***	*F=0.654 p=0.522*	*F=1.583 p=0.209*
Degree of relationship with the patient		
Spouse	99.28±15.73	29.13±16.08
Children	98.83±9.74	33.16±15.91
Mother-father	88.84±24.54	25.75±12.90
Sibling-relative-friend	95.56±15.97	20.81±13.70
[a]**Statistic/*p***	*F=2.337 p=0.077*	*F=1.813 p=0.148*
Living with the patient		
Yes	92.48±23.43	27.80±14.90
No	94.60±16.35	24.04±12.81
[b]**Statistic/*p***	*t=-0.547 p=0.585*	*t=1.446 p=0.151*
Presence of others who are given care		
Yes	99.13±17.98	28.58±16.87
No	91.83±21.88	25.87±13.45
[b]**Statistic/*p***	*t=1.420 p=0.158*	*t=0.903 p=0.368*
Presence of any disease		
Yes	94.65±22.08	33.30±16.16
No	92.87±21.04	24.76±13.28
[b]**Statistic/*p***	*t=0.382 p=0.703*	*t=2.802* ***p=0.006***

Bold values indicate statistical significance, X = Mean, SD = Standard deviation, [a] ANOVA test, [b]Independent simple t test p<0.05 post hoc test

In a qualitative study conducted with Muslim caregivers, it was revealed that the participants had religious/spiritual coping behaviors such as believing in God, praying, and thanking God and that these behaviors facilitated coping (Serçekuş et al., 2014). In this study, the spiritual orientation of the participants was high and their care burden was light. In a study conducted by Küçükoğlu (2019) in Turkey, it was determined that the caregivers of patients receiving chemotherapy had a light care burden. Likewise, it was determined that the care burden of individuals who give care to cancer patients was light-moderate (Berber, 2014; Çeler et al., 2018; Ghori et al., 2020; Kahrıman, 2014; Kaynar &Vural, 2018; Orak & Sezgin 2015).

Although there was no statistically significant relationship between spiritual orientation and care burden, it is thought that the higher the spiritual orientation of patient relatives, the more willing and resilient to meet the care needs of patients, thus reducing care burden. As a matter of fact, spirituality and religion are two concepts that have an important impact on the life of an individual diagnosed with cancer, and they are important components of the well-being of both patients and caregivers (Vardar et al., 2021). In this study, the fact that most of the patients (65.6%) were independent in their daily work and that most of the caregivers had been giving care to their relatives for 1-6 months might have been effective in the light care burden of the participants. As a matter of fact, studies showed that the care burden of caregivers of individuals receiving chemotherapy increases during treatment (Küçükoğlu, 2019; Özdemir et al., 2017; Özdemir, 2018; Palos et al., 2011; Şahin et al., 2009).

All the problems experienced during the treatment process of the cancer patient affect the care burden and some characteristics of the caregiver affect his/her care burden. In this study, it was determined that education level, perception of income level, family structure, and current disease status affect the care burden. In many studies, it was reported that the socio-economic status of the caregiver, health status, education level, needs of the caregiver, the duration of caregiving, the status of receiving help during care, interaction with the care-receiver, the status of living together, and responsibilities other than patient care affect the care burden (Al-Daken & Ahmad, 2018; Koç et al., 2016; Seo & Park, 2019; Williams, 2018).

In caregivers of patients with low-income levels, caregiver burden, anxiety, and depression score medians were higher than those with moderate- and sufficient-income levels and caregiver burden was higher in caregivers with low income (Berber, 2014; Küçükoğlu, 2019; Türkoglu & Kılıç, 2012; Yurtseven, 2018). Likewise, in this study, the care burden of those who perceived their income level as low was higher than those who perceived their income level as moderate.

In this study, it was determined that illiterate individuals had a higher care burden compared to high school graduates. In some studies in the literature, it was determined that there is no significant difference between the caregiver burden and the education level of the caregivers (Ceylan Gür, 2018; Yurtseven, 2018). In some studies, on the other hand, it was found that there is a relationship between education level and care burden and that primary school graduates perceive a high level of care as a burden compared to university graduates (Özdemir, 2018; Yıldız et. al., 2016). It is thought that education level affects the perception of the disease and treatment process and is effective in the problem-solving skills of individuals.

Limitations and Strengths of the Study

This study has some limitations. This study is limited to the population from which research data were collected and cannot be generalized to all caregivers of cancer patients. The entire population from which the research data were collected is Muslim. This might have affected the research results. This study is limited to the data collected with two scales

CONCLUSION

As a result of this study, it was determined that the relatives of patients receiving chemotherapy had a very high spiritual orientation and that the majority of them had a light care burden. However, no relationship was found between their spiritual orientation and care burden. In line with these results, nurses are recommended to consider the needs of individuals who give care to cancer patients receiving chemotherapy as much as patients in their care plans, be aware of the contribution of spiritual care to coping with the process, and support their spiritual orientation. It can be suggested to repeat the study in populations with different cultures and religious beliefs.

ETHICAL APPROVAL

This study was approved by Aydın Adnan Menderes University Nursing Faculty Non-Invasive Clinical Research Ethics Committee (Ethics committee no: E-76261397-050.99-133536, 05.02.2022). Written institutional permission was taken from the hospital where

the study was conducted. Participants were informed about the study and its purpose and their verbal consent was taken. This study was carried out based on the principles of the Declaration of Helsinki.

AUTHOR CONTRIBUTIONS

Idea, concept and design: ET, YD. EÖ.
Data collection and analysis: ET, YD. EÖ.
Drafting of the manuscript: ET, YD
Critical review: ET, YD

CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

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