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Determining the Care Burden and Burnout Levels of Family Members Providing Care for Cancer Patients

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ABSTRACT

Objectives: Caregivers' care burden and burnout levels are projected to increase as the physical independence of their patients decreases. This study aimed to determine the care burden and burnout perception of caregivers of cancer patients.

Methods: The study was conducted with 143 patient relatives who were providing primary care for patients treated between March 1 and June 1, 2017, in the clinics of the Institute of Oncology of Istanbul University. The data were collected using the " Personal information form ", "Zarit Caregiver Burden Scale" and "Maslach Burnout Inventory". Data were analyzed using the SPSS statistical program. Descriptive statistics (frequency, percentage, mean, minimum, maximum, standard deviation) student t-test, one-way ANOVA, and Pearson correlation coefficient were used for data analysis.

Results: The mean score from the burden interview was found 27.38±17.04. In the burnout inventory results, the mean of emotional exhaustion is 19.61±9.08, the mean of depersonalization is 8.78±5.38, and the mean of decrease in personal accomplishment is 29.66±5.91. Individuals' perceptions of emotional exhaustion and depersonalization increase as their perception of care burden increases (p<.001). There was, however, no relationship between care burden and personal accomplishment (p>.05). The study demonstrated that caregivers' care burden and burnout perceptions increased as cancer patients' self-care ability worsened (p<.01).

Conclusion: It has been found that the perceived care burden level is low and burnout level is middle among the caregivers of cancer patients. The patients' level of dependency increases perceptions of caregiver burden and burnout increases too.

Keywords: Cancer patient, family, care burden, burnout, oncology

1. INTRODUCTION

Cancer is a life-threatening disease with increasing prevalence worldwide and is one of the most important diseases today. The process of diagnosing and managing the disease and patient care represents a very difficult period for the patients and their families. Family members providing care for the patients may feel physically and emotionally exhausted (1). As the patients lose their ability to function independently, their care is assumed by another person (2). Caregivers must also take on the responsibility of care. Caregiving starts when the patient's condition progresses, gets worse and symptoms deteriorate. Caregivers empathize with the patients, and they may experience feelings of self-respect and satisfaction with the self, but may also suffer from negative feelings due to personal or extraneous causes, as their experience, communication and personal development improve as they provide care. (3). Monetary problems, psychological problems, and patient burnout may particularly lead to an unfavorable course of events for the patient and the caregiver (4).

Care of the patients diagnosed with cancer is undertaken by their family members. Caregiving may be a financial and psychological burden for caregivers. The care burden is even greater for the relatives of terminally ill patients. The fact that the psychological state of the caregiver is affected in the caregiving of terminally ill patients adds further to the caregiving burden (5). Studies have shown that women constitute the majority of caregivers in many countries (4,5). Compassion and affection which are characteristics of women are regarded as key perceptions leading them to assume patient care. In addition, women can undertake care duties better and find solutions to any problems they may encounter faster than men. However, male caregivers have a stronger mood than female caregivers (3).

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Limitations in a Caregiver's life can increase anxiety and the perception of depression, causing the person to feel burnout. Burnout is defined as the state where varied resources the individual has are about to be depleted, and the individual is in a constant condition of being unhappy and having negative feelings in daily living. Individuals experiencing burnout syndrome are those with diminished life energy who feel desperate against life and make no effort to get their lives back on track (6). Physical and psychological problems the caregivers of cancer patients experience and the limitations to their activities of daily living may increase their anxiety and depression perception and may thus lead the caregivers to feel exhausted. The changing social relations and roles the caregivers undertake and the economic problems they experience may enhance burnout perception. This may have negative consequences on the well-being of both the caregiver and the patient. It is therefore essential to determine the caregiver's perceived burnout and to take precautions accordingly (6). This study aims to determine the care burden and burnout perception of caregivers of cancer patients.

2. METHODS

2.1. Design and Sample

The study was performed in a descriptive and cross-sectional design to determine the care burden and burnout perception of caregiving family members of cancer patients. The population of the research consists of 156 patient relatives who provide care to patients receiving treatment recorded at Istanbul University Oncology Institute clinics between March 1 and June 1, 2017. In the power analysis that has been made, it has been discovered that the sample size is α=.05, and the significance level is 1-α=.95 confidence interval β=.10 error risk is 1-β=.90 and the total number of subjects is 110. Research has been made with the 143 patients' relatives who provide primary care for the cancer patient. The patient relatives included in the study were above 18 years of age, had no communication problems, and agreed to take part in the study.

2.2. Research Questions

Is the care burden of caregivers increasing for cancer patients who cannot meet their self-care needs?

Is the perception of burnout increasing among caregivers of cancer patients who cannot meet their self-care needs?

Does the burnout of individuals caring for cancer patients increase as the care burden increases?

2.3. Data Collection

After obtaining the approvals of the ethics board and the institution, the patient's relatives were explained the purpose of the study, their written consents were received, and the personal information forms were completed using the face-to-face interviewing method. The data were collected using the " Personal information form ", "Zarit Caregiver Burden Scale" and "Maslach Burnout Inventory".

2.3.1. Personal information form

There are total of 23 questions in the personal information form including 9 questions regarding the sociodemographic characteristics of the participants, 8 questions regarding the individual characteristics of the caregiver, and 6 questions regarding the person's level of relationship with the caregiver.

There is also a question assessing 9 self-care needs. In this question, patients who perform self-care activities without support are considered independent, and patients who need support are considered dependent.

2.3.2. Zarit Caregiver Burden Scale

Developed in 1980 by Zarit et.al. to evaluate the stress of caregivers, the scale includes 22 questions. Scores from the scale increase with increasing distress experienced in caregiving (7). The internal consistency coefficient of the scale was found to range between .87 and .94. The validity and reliability of its Turkish adaptation were established the 2008 year (8). The Cronbach's alpha coefficient of the scale was .81 in the present study.

2.3.3. Maslach Burnout Inventory

The inventory comprises 22 questions. It is a Likert-type scale, scored from 0 to 5 as never, a few times a year, a few times a month, a few times a week, and every day. It has three sub-dimensions, i.e. "Emotional exhaustion" including 9 items (1, 2, 3, 6, 8, 13, 14, 16, 20), "Depersonalization" including 5 items (5, 10, 11, 15, 22) and "Reduced personal accomplishment including 8 items (4, 7, 9, 12, 17, 18, 19, 21). Emotional exhaustion and Depersonalization include negative, and reduced personal accomplishment includes positive responses. Low reduced personal accomplishment and high emotional exhaustion and depersonalization indicate a high level of burnout. To rate, three separate burnout scores are calculated for each individual. Responses were scored on a six-point likert scale (ranging from 0 = never to 6 = everyday) for each subscale and tabulated into three tiers (low, moderate, or high) based on the reference ranges provided with the Maslach Burnout Inventory: for emotional exhaustion, low (0–16), moderate (17–26) and high (≥27); for depersonalization, low (0–6), moderate (7–12) and high (≥13), and finally, for personal accomplishment, low (≤31), moderate (32–38) and high (≥39). Capri found a Cronbach's alpha internal consistency coefficient of .93. (9). Internal consistency coefficients for sub-dimensions were .83, .75, and .88 respectively. In this study, Cronbach's alpha coefficients were .82 for emotional exhaustion, .86 for depersonalization, and .85 for reduced personal accomplishment.

2.4. Ethical Considerations

This study was taken with the consent of the Marmara University Institute of Health Sciences ethics committee (No: 11, Date: 28.03.2016). It was compatible with Helsinki Declaration policies.

2.5. Statistical Analysis

Data were analyzed using the SPSS statistical program. Descriptive statistics (frequency, percentage, mean, minimum, maximum, standard deviation) student t-test, one-way ANOVA, and Pearson correlation coefficient were used for data analysis. The level of significance was set at p<.05.

2.6. Limitations of the study

Due to the long duration of cancer treatments, patient circulation in oncology clinics is low. For this reason, the study was conducted with a limited number of patients.

3. RESULTS

Of the respondents, 66.4% were female, 46.2% were aged 30 years and below, 46.9% had bachelor's degrees, 87.4% were urban residents, 60.1% had mid-level income, 73.4% were staying with the patient at night, 64.8% had a constant place of residence with the patient, and 72.7% were not responsible for providing care for another individual. Of the respondents, 54.5% were providing care for a first-degree relative, 86.7% received assistance in caregiving and 39.9% spent more than 18 hours of their time with the patient. Of the patients the respondents provided care for, 52.4% were male, 73.5% were aged 30 years and older, 33.6% had breast cancer, 59.4% had had the disease for 0-6 months and all had social security. Of them, 46.9% were dependent on others in eating and drinking, 67.1% in bathing/showering, 65% in dressing up/grooming, 60.1% in going to the toilet, 68.5% in walking/strolling, 70.6% in climbing upstairs, 73.4% in shopping, 85.3% in cooking and 87.4% in maintaining the household. Patients' and caregivers' sociodemographic data are provided in Table 1.

The mean score from the caregiver burden scale was detected as 27.38±17.04, under this circumstances care burden for the respondents is low. In the providing care scale, the situation of being dependent on the relative has the highest interval with 2.47±1.62 and the situation of taking care of someone else than the relative has the lowest interval with 0.46±0.82.

Patient relatives who were aged 31 to 45 years had a higher perception of care burden compared to others (p<.001). There is a significant difference between the occupation and the perceived care burden of the caregiver (p<.001). Workers and civil servants have a higher care burden perception than members of other occupations. There is a difference between the age of the patient cared for and the perceived care burden (p<.001). Individuals providing care for patients aged 61 years and above have higher perceptions of care burden compared to other age groups. Individuals providing care for patients who had been diagnosed 2 years ago and more also have higher perceptions of care burden. There is a difference between each of the items in self-care of the patient cared for and perceived care burden (p<.001). The care burden increases as the ability of patients to perform self-care tasks decreases. The difference between patients' ability to perform self-care tasks and the care burden perceived by the caregiver is shown in Table 2.

Table 1. *Sociodemographic Characteristics Distribution of Caregivers and Patients (N=143)*

Characteristics	n	%
Caregivers		
Gender		
Female	95	66.4
Male	48	33.6
Age		
30 years and below	66	46.2
46 years and above	49	34.2
31-45 years	28	19.6
Occupation		
Student	38	26.6
Worker	29	20.3
Housewife	28	19.6
Civil servant	19	13.3
Other	19	13.2
Retired	10	7
Social Security		
Yes	134	93.7
No	9	6.3
Patients cared for		
Gender		
Male	75	52.4
Female	48	47.6
Age		
45-60 years	39	27.3
61 years and above	39	27.3
30 years below	38	26.5
31-45 years	27	18.9
Diagnosis		
Breast	48	33.5
Lung	19	13.3
Bone	18	12.6
Testicular Tumor	17	11.9
Colon	10	7
Pancreas	10	7
Ovary	10	7
Liver	9	6.3
Ewing Sarkom	2	1.4
Disease Duration		
0-6 months	85	59.4
2 years and above	29	20.3
6-12 months	19	13.3
1-2 years	10	7

Table 2. *The difference between patients' ability to perform self-care tasks and care burden perceived by the caregiver (N=143)*

Self-care behaviors	Mean ± SD		t	p
	Dependent	Independent		
Eating/drinking	58.12±22.52	42.71±26.81	5.78	.000*
Bathing/showering	54.58±23.14	39.74±23.14	5.27	.000*
Dressing up/grooming	56.21±21.53	38.21±23.08	6.25	.000*
Going to the toilet	55.21±22.48	38.18±21.84	5.95	.000*
Walking/strolling	56.21±25.64	40.21±25.30	5.65	.000*
Climbing upstairs	59.22±23.47	41.63±26.57	6.2	.000*
Shopping	60.18±21.57	37.24±19.71	6.02	.000*
Cooking	59.61±20.39	41.68±24.93	6.1	.000*
Maintaining the household	61.24±20.74	36.14±21.66	6.21	.000*

*Note. SD = standard deviation; *p<.001.*

As for the results of the burnout inventory; the mean emotional exhaustion score was detected as 19.61±9.08, the mean depersonalization score was detected as 8.78±5.38 and the mean reduced personal accomplishment score was detected as 29.66±5.91. Caregivers have the middle perception of burnout. There is a difference between emotional exhaustion and caregiver gender (p<.001) while there is no difference between patient family member gender and depersonalization or reduced personal accomplishment (p>.05). Perception of emotional exhaustion is higher among women. There is a difference between the social security status of the caregiver and emotional exhaustion and depersonalization (p<.001), while social security status and reduced personal accomplishment are not significantly related (p>.05). Emotional exhaustion and depersonalization perceptions are higher in caregivers without social security. There was a difference between emotional exhaustion and depersonalization and income status (p<.001), but no difference between income status and reduced personal accomplishment (p>.05). Perception of emotional exhaustion and depersonalization is higher in those with low levels of income. Emotional exhaustion and depersonalization perceptions are higher in the absence of individuals assisting in patient care. There is a significant difference between each of the items in the ability of the patient cared for to perform self-care tasks and perceptions of emotional exhaustion, depersonalization, and reduced personal accomplishment (p<.001). Caregivers of patients who are dependent on others in eating/drinking, bathing/showering, dressing up/grooming, going to the toilet, walking/strolling, climbing upstairs, shopping, cooking, and maintaining the household have higher perceptions of emotional exhaustion, depersonalization, and reduced personal accomplishment. The difference between the ability of the patients cared for to perform self-care tasks and the burnout perceived by the caregivers is provided in Table 3.

Table 3. *The difference between the ability of the patients cared for to perform self-care tasks and burnout perceived by the caregivers (N=143)*

Self-care behaviors	Sub-dimensions	Mean ± SD		t	p
		Dependent	Independent		
Eating/ drinking	Emotional exhaustion	22.16±8.25	17.36±6.54	3.25	.001**
	Depersonalization	9.52±5.64	8.12±4.52	3.52	.000*
	Decrease in personal accomplishment	31.63±8.52	27.43±5.63	4.35	.000*
Bathing/ showering	Emotional exhaustion	23.21±6.85	16.17±7.85	4.52	.000*
	Depersonalization	10.25±4.52	7.82±5.63	4.53	.000*
	Decrease in personal accomplishment	31.57±6.54	27.38±7.45	4.52	.000*
Dressing up/ grooming	Emotional exhaustion	24.17±7.52	15.24±4.31	4.63	.000*
	Depersonalization	11.25±3.54	6.54±3.82	5.65	.000*
	Decrease in personal accomplishment	30.60±7.12	26.46±8.63	4.37	.000*
Going to the toilet	Emotional exhaustion	23.18±7.64	16.21±7.64	4.51	.000*
	Depersonalization	11.62±4.63	6.22±3.71	5.61	.000*
	Decrease in personal accomplishment	32.64±8.63	26.42±6.97	4.55	.000*
Walking/ strolling	Emotional exhaustion	22.51±9.12	17.54±8.25	3.65	.000*
	Depersonalization	10.20±5.28	7.80±4.23	4.32	.000*
	Decrease in personal accomplishment	31.61±7.92	27.44±8.52	4.22	.000*
Climbing up stairs	Emotional exhaustion	21.65±7.56	18.14±7.23	3.15	.000*
	Depersonalization	10.55±5.34	7.24±3.10	4.86	.000*
	Decrease in personal accomplishment	31.59±9.52	27.36±9.46	4.65	.000*
Shopping	Emotional exhaustion	24.53±5.31	15.30±3.69	4.63	.000*
	Depersonalization	9.54±4.39	8.10±2.54	3.61	.000*
	Decrease in personal accomplishment	30.58±7.22	26.48±8.22	4.69	.000*
Cooking	Emotional exhaustion	25.54±4.82	16.54±5.12	5.21	.000*
	Depersonalization	9.64±3.91	8.00±3.17	3.54	.000*
	Decrease in personal accomplishment	31.62±8.46	27.43±6.17	4.29	.000*
Maintaining the household	Emotional exhaustion	25.94±9.21	16.21±4.54	5.65	.000*
	Depersonalization	10.25±3.82	7.54±2.92	4.64	.000*
	Decrease in personal accomplishment	31.58±9.11	27.37±9.38	4.36	.000*

*Note. SD = standard deviation; *p<.001; **p=.001.*

When the relationship between burnout perception and care burden perception was examined, a statistically significant relationship was found between caregivers' perceptions of burden, emotional exhaustion, and depersonalization (p<.001). Perceptions of emotional exhaustion and depersonalization intensified as the care burden increased. Care burden and reduced personal accomplishment, however, were not significantly related. The relation between caregivers' perceptions of burnout and care burden is presented in Table 4.

Table 4. *The relation between caregivers' perceptions of burnout and caregiver burden (Pearson correlation test) (N=143)*

Burnout subdimensions		
Emotional exhaustion	r	0.816
	p	.000 *
Depersonalization	r	0.571
	p	.000 *
Decrease in personal accomplishment	r	0.049
	p	.573

*Note. *p<.001.*

4. DISCUSSION

Our study demonstrated that the majority of the people assuming the care of cancer patients were women, which was consistent with the literature (Table 1) (10,11). Because of the compassion and affection inherent to the nature of women, women undertake the caregiving responsibility in our society. Given the responsibilities taken by women within the family, it is possible to consider them as being better fitting for the caregiving task. Caregivers of cancer patients were aged between 40 and 55 in many studies in the literature (11) ,whereas the corresponding age group was 30 years and below in our study (Table 1). The caregiver within a family is likely chosen from the younger and more vigorous members considering the complicated nature of cancer and the difficulties in its care, which may require a more quick-acting individual in the face of an unusual situation. Of the patients cared for, 52.4% were male 27.3% were aged between 45 and 60 and 27.3% were above 61 years. Based on the American Cancer Society data , cancer has a higher incidence after 40 years of age. It is also estimated that more than half of cancer patients are 65 years and above. Breast cancer, the most common type of cancer, was seen in 33.6% of the patients receiving care (12). Patients who are being given care are dependent on others to perform self-care tasks. According to the Family Caregiver Alliance trial, cancer patients fall short in self-care and have high care needs (4).

It was determined that the burden of care perceived by the patient's relatives who participated in the survey was low. Similarly, in the literature, the perceived care burden for caregivers of cancer patients was found to be low. (13). We believe that the perception of caregiver burden was low because caregivers were young and the patients cared for were mostly newly diagnosed. Individuals providing care for 2 years or more have a higher care burden perception. The caregiver's struggle together with a patient increases the perception of care burden. Consistent with our study, several studies have reported increased care burden with longer disease duration (3,14,15)

There is a difference between each of the items in self-care of the patient cared for and the perception of care burden (p<.001) (Table 2). Perception of care burden is higher in caregivers of patients who were dependent on others in eating/drinking, bathing/showering, dressing up/grooming, going to the toilet, walking/strolling, climbing upstairs, shopping, cooking, and maintaining the household. We believe that caregivers experience further difficulties when the conditions of the patients cared for progress and deteriorate and their symptoms worsen.It has been detected that the burnout perception of caregivers is middle. We believe that burnout perception was middle because patients cared for were mostly newly diagnosed patients and caregivers assumed this role not too long ago. In the literature, it is seen that caregivers of patients experience psychological problems (3). Perceptions of emotional exhaustion, depersonalization, and reduced personal accomplishment differ by whether the caregiver shares the same house with the patient as well as the daily time the caregiver spends with the patient. It has been determined in the literature that caregivers' inability to spare enough time for themselves because they spend too much time on patients increases the perception of burnout (15). In addition, not having someone to assist in patient care and assuming the care of the sick relative alone also increases perceived emotional exhaustion and depersonalization. It has been determined in the literature that individuals who do not receive support in meeting their care needs are more psychologically affected (11). There is a difference between the ability of the patient to perform self-care tasks and the perception of burnout (p=.001) (Table 3). Caregivers of dependent patients had higher perceptions of emotional exhaustion, depersonalization, and reduced personal accomplishment. We believe that caregivers not only experience physical difficulties as a result of the patient not being able to maintain self-care but also perceive burnout because of the sadness of seeing the dependency of the patients who once carried out all their tasks on their own.

There was a relationship between perceived care burden emotional exhaustion and depersonalization. Increased care burden led to an increased perception of emotional exhaustion and depersonalization. On the other hand, care burden and reduced personal accomplishment were not significantly related (Table 4). We believe that caregivers' perceived personal accomplishment is not affected by the positive experiences including their empathy for the patient, personal satisfaction, increased experience, communication and personal development going further as they provide care, and their growing self-respect. There are many studies in the literature describing the negative impact of increased care burden on caregivers' psychology. As the care burden increases, perceptions such as burnout, stress, fatigue, and weariness intensify as well (3,11,14,16).

5. CONCLUSION

It has been found that the perceived care burden level is low and burnout level is middle among the caregivers of cancer patients. Caregivers' care burden and burnout levels increase as patients' dependency increases. Caregivers' perceptions of emotional exhaustion and depersonalization also increase with increasing care burden whereas perceived personal accomplishment is not altered. Caregivers should not be forgotten while providing care for the cancer patient. Caregivers should be informed about the care, general health condition, and the use of resources. Parents and group meetings can increase the care quality by alleviating the caregivers' burden. This research has been done in the university hospital. The differences can be discovered by doing studies in private and public hospitals.

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