

Original Article

Examination of the Care Burden of Caregivers of Oncology Patients and the Perceived Social Support from Family

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Abstract

Aim: This study was conducted to examine the care burden of caregiving family members of oncology patients and the perceived social support from family.

Methods: The study was conducted as a descriptive and correlational study. The population of the study consisted of caregiving family members of patients who were receiving treatment in the medical oncology clinic of a university hospital between January and July 2014. The sample of the study was determined as 150 by using the sampling method with finite population and the randomized method. The data were collected by using 'Questionnaire, 'Burden interview', and 'Perceived Social Support from Family Scale'.

Results: In the study, total mean score obtained by caregiving family members were determined as 25.00 ± 13.59 in the Burden Interview and 8.00 ± 1.60 in the Perceived Social Support from Family Scale. The values showed that while the care burden was high; the perceived social support from family was low. There was a negative correlation between the Care Burden of caregiving family members and the Perceived Social Support from Family. It was determined that as the care burden increased, the Perceived Social Support from Family decreased.

Discussion: In the study, it was found that while the care burden of the caregiving families was high, their perceived social support from family was low.

Keywords: Caregiver, Care Burden, Oncology Patients, Social Support

Introduction

Cancer is an important physical and emotional health problem that threatens community health worldwide and affects both patients and patient relatives (Lepore, Lieberman & Golant 2014; Given 2016). Prevalence of cancer types has also increased together with the extension of human life (Sultan, Efe & Korukuluoglu 2008). In recent years, cancer has showed an increase at the rate of 1-2% worldwide. According to the data of 2012; there were 14.1 million cancer cases in the world and 8.2 million people died due to cancer

(WHO 2012). There is a parallelism process between the diagnosis of cancer and caregiving roles of family members (Oksuz 2013). Families are considerably needed by patients both during their treatment at the hospital and at home care. Patients are discharged at the end of their treatment processes at the hospital and their care continues at their own home (Tan 2007).

Considering the decrease in ambulatory care and medical resources; family undertakes a more central role in patient care (Given 2016). Families provide care to patients in matters such

as transportation, cleaning, treatment, and personal care (Yong, Jiao & Jianhui 2015). While giving care to patients with cancer at home; families leave aside their own health and needs, devote all their energy to patients and deal with their care, needs and treatment (Dayapoglu & Tan 2010; Lambert, Yoon, Ellis & Northouse 2015). Family members are affected by long-term care and experience stress (Yarbro 2003). As a result of a study concerning the care burden of families, it was determined that the symptoms and severity of disease affected the care burden (Stenberg, Ruland & Miaskowski 2010). Thus, caregiving families also need support and strengthening (Terakye 2011).

The perceived social support from family has a positive effect on physical and mental health (Gallant, Sheehan, Shaver & Bailey 2015; Gustavsson, Gremyr & Kenne 2015). As caregivers are affected both physically and psychologically in treatment of cancer, the perceived social support from family is highly important (Nijboer, Tempelaar, Sanderman & Triemstra 1998). As the social support of caregivers increases, the despair shown towards patients also decreases (Tan & Karabulutlu 2005). Recent studies have revealed that as the perceived social support from family increases in caregivers of patients with cancer, patients overcome this challenging process more easily (Suwankhong & Liamputtong 2016; Requena, Arnal & Gil 2013; Ward, Chiarello, Bartlett, Palisano & McCoy 2014). In their study, Akbiyik et al., proved that caregivers' the perceived social support from family had a positive effect on patients with cancer, as well as their mental status (Akbiyik, Soygur & Karabulut 2012).

Since especially patients in Turkey live with their families and their families are liable for their care, there is a greater need for social support. In their study, Dedeli et al., observed that there was a positive correlation between the perceived social and emotional support from family and well-being of patients with cancer (Dedeli & Karadeniz 2009). As the perceived social support from family increases for caregivers, the support of patients aimed at coping with the effects of disease and treatment and increasing the level of hope increases.

There is a limited number of researches on care burden of caregivers of patients with cancer in the world and in Turkey; however, there is no study on the care burden and the perceived social

support from family (Lee, Chang, Chou & Su 2013; Kim, Shaffer & Carver 2014; Rha, Park & Song 2015). This study examines the care burden and the perceived social support from family. The study results are expected to make a contribution to the practices to be performed in this field.

This study was conducted to examine the care burden of caregiving family members of oncology patients and the perceived social support from family.

Method

Participants and procedure

The study was conducted as a descriptive and correlational study. The study was conducted on caregiving family members of patients who were hospitalized in the medical oncology service of a university hospital between January and July 2014. The population of the study consisted of adult caregiving family members of patients who were receiving treatment in the medical oncology service of a university hospital. The sample of the study consisted of 150 caregiving family members by using the sampling method with finite population and the randomized method. The Inclusion Criteria; being the primary responsible for patient care, being open to communication. The data were collected from family members by the researcher in a room located in the medical oncology service through face-to-face interview method. It took averagely 20-25 minutes to complete each questionnaire.

Instruments

Questionnaire

The questionnaire involved 13 questions about the descriptive characteristics of the patients and their caregiving family members.

Burden interview

Burden interview was developed by Zarit Orr and Zarit in 1985. The Turkish validity and reliability study of the clinically adapted form was conducted by Ozer et al., in 2005. Comprising 14 items; the Clinically Adapted Burden interview (CBI) involves scores between 0 and 4 for each item and while the lowest score to be obtained from the scale is 0, the highest score is 56. 0 signifies "Never", 1 "Rarely", 2 "Sometimes", 3 "Frequently", and 4 "Almost always". CBI where all the items are expressed flatly is evaluated on the basis of the total score.

As the score increases, the care burden also increases (Ozer, Yurttas & Akyıl 2012). In the study, the cronbach alpha coefficient of the scale was determined as 0.92.

The Perceived Social Support from Family Scale

Being developed by Procidano and Heller; Eskin (1993) translated the Perceived Social Support from Family Scale into Turkish and conducted its validity study. The scale comprises 20 items to be answered by marking one of options as “yes”, “no” and “I don’t know”. The reaction showing the perceived social support is scored as “+1” for each item. The scores vary between 0-20. The option “I don’t know” is not scored. In the scale, the items 3,4,16, and 19 are reverse items. In these questions, the option “no” is scored as +1. Highness of the score signifies the highness of the perceived social support from family. The Cronbach alpha internal consistency of the scale was 0.85 (Dayapoglu & Tan 2009). In the study, the Cronbach alpha coefficient of the scale was determined as 0.87.

Data Analysis

The data were assessed by using percentage, mean, independent samples t-test, analysis of variance and correlation.

Ethical Considerations

In order to conduct the study, a written permission was obtained from the relevant institution. The caregiving family members included in the study were informed about the aim of the study and their verbal consents were received.

Results

Table 1 shows the descriptive characteristics of the patients and the caregiving family members in the study. The patients participating in the study had an age average of 51.00 ± 15.64 . 50.7% of them were female, 78.7% were married, and 34.7% were primary school graduates. 30.7% of the patients had lung Ca. 52.7% of the family members were female, 66.7% were married and 29.3% were primary school graduates. In the study, 68.7% of the family members stayed with their patients and 82.6% had knowledge about patient care. (Table 1)

Table 2 illustrates the comparison of total mean score of the Burden Interview according to the descriptive characteristics of the patients in the

study. A statistically significant difference was found between the mean scores of Care Burden in terms of the medical diagnoses of the patients in the study ($p < 0.05$, Table 2).

Table 3 illustrates the comparison of total mean scores of the Perceived Scale of Social Support from Family in terms of descriptive characteristics of the patients in the study. In the study, a statistically significant difference was determined between total mean scores of the Perceived Social Support from Family Scale in terms of the patient’s educational level, duration of disease and caregiver’s working condition ($p < 0.05$). As the duration of disease increased, caregiving family members’ perceived social support from family decreased (Table 3).

Table 4 shows the comparison of total mean scores of the Burden Interview and the Perceived Social Support from Family Scale in the study. Examining the correlation between the Care Burden and the Perceived Social Support from Family; it was determined that as the care burden increased, the perceived social support from family negatively decreased (Table 4).

Discussion

The results of this study, which was conducted for the purpose of examining the care burden of caregiving family members of oncology patients and the perceived social support from family and the informational and educational needs of family members were about the progress of patient health, treatment, nursing care and general care, were discussed with literature knowledge (Astedt-Kurki 1997, Sapountzi-Krepia et al, 2006, Sapountzi-Krepia et al, 2008, Lavdaniti, et al, 2011, Stavrou et al, 2014).

Examining the descriptive characteristics in the study; majority of the patients and caregiving family members were found to be female, married and primary school graduates (Table 1). The study results show a similarity with literature (Requena, Arnal & Gil 2013; Ward, Chiarello, Bartlett, Palisano & McCoy 2014; Waters, Liu, Schootman & Jeffie 2013; Sanuade & Boatemaa 2015). In the study, total mean scores were determined as 25.00 ± 13.59 for the Burden Interview and 8.00 ± 1.60 for the Perceived Social Support from Family Scale. In accordance with these results, it was found that the care burden was high, whereas the perceived social support from family was low.

Table 1. Descriptive Characteristics of the Patients and Family Members

Descriptive Characteristics	n	%
Patient's Gender		
Female	76	50.7
Male	74	49.3
Patient's Marital Status		
Married	118	78.7
Single	32	21.3
Patient's Educational Level		
Illiterate	20	13.3
Literate	28	18.7
Primary Education	52	34.7
High School	32	21.3
University	18	12.0
Patient's Working Condition		
Available	30	20.0
N/A	120	80.0
Patient's Residential Area		
Province	105	70.0
District	20	13.3
Village	25	16.7
Patient's Medical Diagnosis		
Stomach CA	26	17.3
Colon CA	28	25.3
Breast CA	29	19.3
Lung CA	46	30.7
Oesophageal CA	11	7.3
Duration of Disease		
3-12 months	87	58.0
13-24 months	41	27.3
25 months and above	22	14.7
Caregiver's Gender		
Female	79	52.7
Male	71	47.3
Caregiver's Marital Status		
Married	100	66.7
Single	50	33.3
Caregiver's Educational level		
Illiterate	11	7.3
Literate	18	12.0
Primary Education	44	29.3
High School	40	26.7
University	37	24.7
Caregiver's Working Condition		
Available	55	36.7
N/A	95	63.3
State of Staying with Patient in the Residential Area		
Yes	103	68.7
No	47	31.3
State of Obtaining Information about Patient Care		
I have knowledge	62	82.6
I have no knowledge	26	17.3
Did the disease have a negative effect on your role within family		
Yes	90	60.0
No	60	40.0

Table 2. Comparison of Total Mean Scores of the Burden interview in terms of Descriptive Characteristics of the Patients and Caregiving Family Members

Descriptive Characteristics	Total Mean Score of the Burden interview			
	n	X±SD	Test Value	p Value
Patient's Medical Diagnosis				
Stomach ca	26	30.46±16.26	MWU=1.446	38
Colon ca	38	25.68±12.44		
Breast ca	29	25.72±13.50		
Lung ca	46	24.00±13.39		
Oesophageal ca	11	20.18±9.74		
Patient's Gender				
Male	76	25.55±14.22	t=0.545	>0.05
Female	74	25.64±13.01		
Patient's Marital Status				
Married	118	25.17±12.86	t=2.902	>0.05
Single	32	27.15±16.12		
Patient's Working Condition				
Available	30	24.45±14.57	t=1.349	>0.05
N/A	120	25.67±13.22		
Patient's Educational Level				
Illiterate	20	24.25±14.41	MWU=798.179	>0.05
Literate	28	27.57±11.83		
Primary Education	52	27.03±14.53		
High School	32	26.06±11.90		
University	18	19.05±14.54		
Patient's Residential Area				
Province	102	24.45±13.21	MWU=143.797	>0.05
District	23	24.86±10.89		
Village	25	30.96±16.33		
Duration of Disease				
3-12 months	87	26.80±14.76	MWU=148.508	>0.05
13-22 months	41	23.43±12.26		
23 months and above	22	24.86±10.78		
Caregiver's Gender				
Male	71	26.78±13.69	t=0.064	>0.05
Female	79	24.53±13.49		
Caregiver's Marital Status				
Married	100	26.70±13.77	t=0.896	>0.05
Single	50	23.40±13.07		
Caregiver's Working Condition				
Available	48	25.16±13.06	t=0.252	>0.05
N/A	95	26.00±13.59		
Caregiver's Educational Level				
Illiterate	11	23.45±13.85	MWU=948.058	>0.05
Literate	18	32.00±14.60		
Primary Education	44	23.97±14.56		
High School	40	23.97±14.56		
University	37	26.24±13.31		

Table 3. Comparison of Total Mean Scores of the Perceived Social Support from Family Scale terms of Descriptive Characteristics of the Patients and Caregiving Family Members

Descriptive Characteristics	Total Mean Scores of the Perceived Social Support from Family Scale			
	n	X±SD	Test Value	p Value
Patient's Medical Diagnosis				
Stomach ca	26	17.88±2.56	MWU=23.814	38
Colon ca	38	17.63±2.95		
Breast ca	29	18.00±2.54		
Lung ca	46	17.43±2.68		
Oesophageal ca	11	19.00±1.26		
Patient's Gender				
Male	76	17.64±2.64	t=0.662	>0.05
Female	74	17.93±2.63		
Patient's Marital Status				
Married	118	17.63±2.74	t=1.253	>0.05
Single	32	18.34±2.13		
Patient's Working Condition				
Available	30	18.24±2.94	t=0.125	>0.05
N/A	120	17.63±2.52		
Patient's Educational Level				
Illiterate	20	16.20±3.84	MWU=15.001	<0.05
Literate	28	17.75±2.54		
Primary Education	52	17.57±2.50		
High School	32	18.53±1.90		
University	18	18.88±1.77		
Patient's Residential Area				
Province	102	17.86±2.65	MWU=0.221	>0.05
District	23	17.78±2.76		
Village	25	17.48±2.53		
Duration of Disease				
3-12 months	87	17.94±2.85	MWU=26.898	<0.05
13-22 months	41	18.19±1.92		
23 months and above	22	16.40±2.51		
Caregiver's Gender				
Male	71	17.54±2.95	t=3.558	>0.05
Female	79	18.00±2.30		
Caregiver's Marital Status				
Married	100	18.06±2.58	t=1.267	>0.05
Single	50	17.24±2.66		
Caregiver's Working Condition				
Available	48	17.29±3.16	t=4.686	<0.05
N/A	95	18.00±2.37		
Caregiver's Educational Level				
Illiterate	11	17.45±2.38	MWU=10.293	>0.05
Literate	18	17.77±1.83		
Primary Education	44	18.18±2.46		
High School	40	17.55±3.24		
University	37	17.67±2.57		

Table 4. Comparison between Total Mean Scores of the Burden Interview and the Perceived Social Support from Family Scale in Caregiving Family Members

SCALES	Burden interview		
	r	p	TOTAL
	.134*	.031	.517**
			.000
The Perceived Social Support from Family Scale	.075*	.239	.144*
			.038
TOTAL	.118	.056	.536**
			.000

In the study conducted by Lee et al., with the relatives of patients with cancer, they determined that the care burden was high (Lee, Chang, Chou & Su 2013). As a result of the study conducted by Kim et al., on relatives of patients with lung cancer, Kim et al. observed that caregivers had a high care burden (Kim, Shaffer & Carver 2014). In their study on geriatric patients with cancer, Lkhoyaali et al., determined that caregivers had a high care burden (Lkhoyaali, Haj, Omrani & Layachi 2015). In the study conducted by Rha et al., on caregivers of patients with cancer they determined that the care burden was high (Rha, Park & Song 2015). The aforementioned studies show a similarity with the results of this study. The fact that cancer requires a long treatment process causes a physical, psychological and financial exhaustion in patient relatives and negatively affects their quality of life. As well as the responsibilities of caregiver of a patient with cancer; the fact that these patients are completely dependent on caregiving family members and negative effects on caregivers could be considered as the reason for the high care burden. Ambrosi et al., determined that family members play key role caregiving at home (Ambrosi, Biavati, Guarnier, Barelli and et al. 2015).

Requena et al., and Ward et al. determined that the perceived social support from family was low in caregiving family members of different patients with cancer (Requena, Arnal & Gil 2013; Ward, Chiarello, Bartlett, Palisano & Mccoy 2014). In the study conducted by Waters

et al., on patients with breast cancer, they determined that caregivers had a low perceived social support from family (Waters, Liu, Schootman & Jeffie 2013). In Turkey, patients with cancer generally receive care from their families and this situation is perceived as an obligatory situation. The fact that caregiving family member is left alone in this process could be considered as the reason for the low perceived social support from family.

In the study, a statistically significant difference was determined in the care burden of caregiving family members according to the medical diagnosis of patients ($p < 0.05$, Table 3). In the study conducted by Foster et al., on caregivers of patients with cancer, they determined a statistically significant difference in the care burden in terms of the medical diagnosis of the patients (Foster, Bardos & Wilson 2013). This result could be associated with recent diagnosis of cancer and the fact that it has a little effect on daily living activities of patients.

In the study, the difference determined between total mean scores of the Perceived Social Support from Family Scale in terms of patient's educational level, duration of disease, and caregiver's working condition was statistically significant ($p < 0.05$, Table 4). In the study conducted by Dayapoglu and Tan on patients with stroke, they determined a statistically significant difference between the perceived social support from family in terms of the educational level (Dayapoglu & Tan 2009). In

the study conducted by Forsythe et al., on caregivers of patients with cancer, they determined a statistically significant difference between the duration of disease and the perceived social support (Forsythe, Alfano, Kent & Weaver 2014). This result could be associated with long duration of disease, its physical and mental exhaustion in caregivers and the failure of families to provide a social support that would mentally and physically strengthen the caregivers.

In the study, a negative correlation was determined between total mean score of the Burden Interview and total mean score of the Perceived Social Support from Family Scale. As the perceived social support decreased, the care burden increased (Table 5). The support that is provided to caregivers by other family members, friends and environment positively affects their approach toward patients and enables them not to consider providing care to patients as a burden. Thus, feeling less social support may be the reason of the higher care burden.

Consequently, in the study it was determined that caregivers had a high care burden and a low perceived social support. Treatment and care of a patient with cancer require a team work. In accordance with these results, it could be recommended for nurses to determine the problems of both patients and caregivers, meet their needs, and train caregivers regarding patient care.

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