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Abstract

The people providing care for relatives always need support and accompaniment from their families and friends. This study aimed to evaluate the correlation among the care burden, mental health and social support perceptions of the patients' relatives that provide long-term care for patients receiving service from the home care service (HCS) unit in one city. This descriptive study was carried out with the relatives of patients receiving service from home health units. Among the relatives providing care for a total of 859 patients, those that did not comply with the inclusion criteria were excluded, which made a total population of 309 people. Individual information form, burden interview, brief symptom inventory and multidimensional scale of perceived social support were used for the assessment of the data. Descriptive statistics and Spearman's correlation coefficient were used for data analysis. The result showed a positive moderate significant correlation among the burden score, brief symptom inventory subscale and global index scores while, a negative moderate significant correlation was discovered between the family, significant other and multidimensional scale of perceived social support scores. Consequently, as the perceived social support level in the patients' relatives providing care increased, their care burden and mental health problems decreased.

Keywords: care burden, long term care, mental health, social support

Introduction

The increase in old age-disabled and chronic diseased people and the increased demand for care services after discharge, impacted the need for home care services along with the population increase in the world and Turkey.[1] Home care service (HCS) is described as providing health and social services professionally or by the family members in the living environment of the patients to protect, promote and rehabilitate their health.[2] The relatives that provide care may be defined as the relative or friend that meets the basic needs and follows medical care and hospital relations by living with the individual in need of care (with chronic or acute illnesses or disabilities) or allocating some of his/her time for the patient.[3] It is seen that especially among the people, providing long-term care experience caused depression, anxiety, burnout, decrease in physical health, social isolation and economic difficulties due to the burden they experienced.[4] Furthermore, due to the continuity of service need and the fact that the majority of service was provided by the family members, the efficiency of the service significantly affected the quality and satisfaction of life and families of the people in need of care.[5] People that provide care for their relatives always need support and accompaniment from families and friends in order to feel that they are not alone and also to obtain help for subjects such as money, information, education, social and emotional support.[6]

The process of home care giving burden, in terms of both patients and caregivers will have positive results for all parties involved when it is implemented within a certain system at the national level, especially by professionals. Furthermore, it was considered that the studies investigating the correlation between care burden and mental health, including the perceived social support were required to guide in planning and applying the interventions for decreasing the burden of caregivers, protecting their mental health and evaluating the results. This study was to investigate the correlation between care burden and mental health with the perceived social support of the patients' relatives providing long-term care in the HCS unit. The specific objectives were: 1) to assess the correlation of care burden with the perceived social support of patients' relatives in long-term care and 2) to as-

sess the correlation between mental health and perceived social support of patients' relatives in long-term care.

Method

This descriptive study was carried out in the houses of the patients' relatives providing long-term care for the patients that received service from the HCS Unit of Niğde Education and Research Hospital in the city center of Niğde. The population was composed of the patients' relatives (the individual meeting the basic needs of the individual in need of care) providing care for 859 people receiving service from the HCS unit. From the Statistics Unit of Niğde Training and Research Hospital, name/surname, telephone numbers and addresses of the people receiving service from the HCS were obtained. Firstly, people were called by phone and those that met the study criteria were identified. In the telephone interview, the time of the respondents' availability was determined and would be visited at their houses.

The people at and over the age of 18, that have been providing patient care for three months and more, had no communication barrier, were not caregivers providing care for a fee and were volunteers, were included in the study. No sampling was selected from the population therefore, the whole population was included. Among the patients' relatives providing care to a total of 859 patients, those that took on patient care for less than three months (356 people), that applied for short-term home care (137 people), those with hearing and speech impairment preventing communication (12 people), the people providing care for a fee with a professional contract (45 people) were excluded from the study and the population became 309 people.

The study was completed by excluding five people that refused to participate, making a total of 304 (the reaching rate was 98.38%). After providing the required information to the participants for collecting the data, the people were included in the study voluntarily. The authors collected the survey data at a suitable time for the people with face-to-face interview technique, by visiting the houses after the consent was received.

Individual information form: The first part of the form consists of eleven questions for determining characteristics such as the demographic characteristics of the patients' relatives and their affinity degrees, caregiving period and the status of getting help in caregiving. Eight questions for determining the demographic characteristics and diagnosis of the patients were included in the second part.

Burden Interview (BI): Its Turkish reliability and validity study was carried out by İnci and Erdem,[7] and its Cronbach Alpha value ranges between 0.87-0.99. It is composed of 22 items determining the effect of caregiving on the life of the individual. The scale includes Likert type assessment varying from 0 to 4: "never", "rarely", "some-times", "often" and "always". The lowest and highest scores on the scale were 0 and 88 points, respectively. A high score indicates that the problem experienced is high. In scoring, 0-20, 21-40, 41-60 and 61-88 points represented "no care burden", "mild burden", "moderate burden" and "severe burden", respectively. Cronbach's Alpha value of this study was determined to be 0.94.

Brief Symptom Inventory (BSI): BSI is a scale composed of 53 items prepared to reveal psychiatric problems in various medical situations. The scale is composed of nine subscales (somatization, obsessive-compulsive disorder/OCD, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism), three global indices (distress severity index, positive symptom total index, positive symptom distress index) and additional items. Turkish adaptation of the inventory was carried out by Şahin and Batıgün,[8] with minimum and maximum scores of 0 and 212. The high total scores obtained on the scale indicated that the symptoms of possible mental disorders of the individual increase.[8] Meanwhile, Cronbach's Alpha internal consistency coefficients varied between 0.96 and 0.95 for the total score of the inventory and between 0.55 and 0.86 for the subscales. In this study, Cronbach's Alpha internal consistency coefficient was 0.91, which varied between 0.75 and 0.82 for the subscales.

Multidimensional Scale of Perceived Social Support (MSPSS): The Turkish validity and reliability study of the scale was carried out by Eker, *et al*.[9] On the scale composed of 12 items, the participant may get a minimum of 1 point for the sentence he/she disagrees with and a maximum of 7 points for the sentence he/she agrees with. The scale has three subscales, with four items each to determine the family, friend and significant other's support. The lowest score that may be obtained from its subscales is 4 and the highest score is 28. Meanwhile, the lowest score that may be obtained from the overall scale is 12 and the highest score is 84. As the score given for each item increases, the perceived social support also increases.[9] The reliability coefficient of the scale and its subscales is 0.89 for the overall scale and 0.85, 0.88 and 0.92 in the "family", "friend" and "significant other" subscales, respectively. In this study, the Cronbach's Alpha was 0.96 for the total scale, 0.84 in the "family" subscale, 0.83 in the "friend" subscale, and 0.83 in the "significant other" subscale.

The data were analyzed using the statistical software set up of Niğde Ömer Halisdemir University for academic staff. Descriptive statistics (number, percentage, mean) were used for data analysis and the Shapiro-Wilk test was used to test the compatibility of the data with the normal distribution. Furthermore, Spearman's correlation analysis was carried out in the examination of the correlation between care burden, the multidimensional scale of per-

ceived social support and its subscales as most of the data were not normally distributed. In all the statistical analyses, p-value <0.05 values were accepted to be significant.

Results

From this study, it was discovered that 48.0% of the patients' relatives providing care were in the age range of 30-49 years. The population detail was 66.8% were female, 88.5% were married, 24.0% were high school graduates, 52.6% had social insurance and 72.0% were unemployed. The patients' relatives providing care that had less income compared to their expenses were 45.1%, 31.6% were the parents of the patient, 53.6% provided care for 3-12 months, 48.7% received help for care and 38.5% obtained help from their children. The age average of the patients' relatives providing care was 45.85±13.08 years and the average caregiving period was 30.95±50.85 months (Table 1). It was discovered that 58.6% of the patients receiving care were at and over the age of 65, 53.9% were female, 69.1% were married, 36.8% were literate and 46.1% had social insurance. The diagnosis of 17.8% of the patients receiving the care was

chronic obstructive pulmonary disease (COPD), 58.6% had at least one comorbidity, where 37.1% had hypertension. The income of 51.6% of the patients was equal to their expenses and their age average was 65.16±16.98 years (Table 2).

Among brief symptom inventory subscales, the participants obtained the highest and lowest scores from the somatization subscale (4.11±5.19) and the additional items subscale (2.43±2.98), respectively. The total score of the participants for the multidimensional scale of perceived social support was 71.63±18.37 points, obtaining the highest score in the significant other subscales (24.11±6.26). In addition, the score of the burden interview was 25.0±16.09 points (Table 3). It was discovered that 45.1% of the participants had no burden, 36.5% had a mild burden, 16.1% had a moderate burden and 2.3% had a severe burden. In detail, 66.5% of those with a burden had a mild burden, 29.3% had a moderate burden, and 4.2% had a severe burden (Table 4).

Table 1. Distribution of Demographic Characteristics of Caregiver Patients' Relatives (n = 304)

Variable	Category	n	%
Age	18-29	38	12.5
	30-49	146	48.0
	50-64	94	30.9
	≥65	26	8.6
Gender	Male	101	33.2
	Female	203	66.8
Marital status	Single	35	11.5
	Married	269	88.5
Education status	Illiterate	17	5.6
	Literate	67	22.0
	Primary school	58	19.1
	Middle school	41	13.5
	High school	73	24.0
	University	48	15.8
Working status	Full day	77	25.3
	Half day	8	2.6
	Not working	219	72.0
Income status	Income is less than expenses	137	45.1
	Equal to the expense income	134	44.1
	Income is more than expenses	33	10.9
Degree of affinity with the patient	Parents	96	31.6
	Children	20	6.6
	Partner	92	30.3
	Relative	34	11.2
	Spouse's parents	62	20.4
Provided care time	3-12 months	163	53.6
	13-24 months	61	20.1
	25-48 months	35	11.5
	≥49 months	45	14.8
The people taken to help care	Partner	35	23.6
	Parents	14	9.5
	Children	57	38.5
	Caregiver	22	14.9
	Sibling	20	13.5

Table 2. Distribution of Demographic Features of Patients Receiving Care (n = 304)

Variable	Category	n	%
Age	≤ 29	17	5.6
	30-49	28	9.2
	50-64	81	26.6
	≥65	178	58.6
Gender	Male	140	46.1
	Female	164	53.9
Marital status	Single	27	8.9
	Married	210	69.1
	Divorced/widowed	67	22.0
Education status	Illiterate	86	28.3
	Literate	112	36.8
	Primary school	57	18.8
	Middle School	15	4.9
	High school	24	7.9
	University	10	3.3
Disease diagnosis	Diabetes mellitus	28	9.2
	Hypertension	15	4.9
	Stroke	41	13.5
	Chronic obstructive pulmonary disease	54	17.8
	Chronic renal failure	8	2.6
	Heart disease	41	13.5
	Asthma	21	6.9
	Alzheimer	11	3.6
	Cancer	19	6.3
	Lumbar disc hernia	9	3.0
	Fracture	45	14.8
	Disabled	12	3.9
Additional diseases	Diabetes mellitus	27	15.2
	Hypertension	66	37.1
	Chronic obstructive pulmonary disease	11	6.2
	Diabetes mellitus-Hypertension	35	19.7
	Asthma	15	8.4
	Heart disease	11	6.2
	Other*	13	7.3
Income status	Income is less than expenses	125	41.1
	Equal to the expense Income	157	51.6
	Income is more than expenses	22	7.2

Note: *Stroke (5), Chronic Renal Failure (2), and Cancer (6)

Table 3. Distribution of the Scores from the Scales and Sub-Dimensions Used in the Study

Scale and Sub-Dimension	Min - Max	Mean ± SD
Somatization	0-28	4.11±5.19
Obsessive-compulsive disorder	0-24	3.78±4.54
Interpersonal sensitivity	0-16	2.60±3.14
Depression	0-24	3.81±4.53
Anxiety	0-24	3.63±4.62
Hostility	0-20	3.01±3.64
Phobic anxiety	0-20	3.01±3.73
Paranoid ideation	0-20	3.19±3.55
Psychoticism	0-20	2.70±3.27
Additional items	0-16	2.43±2.98
Distress severity index	0-3.47	0.53±0.59
Symptom total index	0-56	20.12±15.76
Symptom distress index	1-4	1.42±0.58
Multidimensional scale of Perceived Social Support–Total	12-84	71.63±18.37
Family	4-28	24.01±6.07
Significant other	4-28	24.11±6.26
Friend	4-28	23.52±6.82
Care Burden–Total	0-70	25.00±16.09

Note: SD: Standard Deviation

Table 4. Distribution of the Care Burden Scale Scoring (n = 304)

Scoring	n	%
No burden	137	45.1
Mild burden	111	36.5
Moderate burden	49	16.1
Severe burden	7	2.3

The positive moderate significant correlation was discovered between burden score and somatization, OCD, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism, additional items, distress severity index, positive symptom total index and positive symptom distress index (p-value <0.01). The burden score was directly proportional to the above listed scores e.g., an increase in the burden score leads to an increase in the other scores (Figure 1). While a negative weak correlation was discovered between the family, significant other and multidimensional scale of perceived social support total scores, a moderately significant correlation was discovered between the family, significant other, multidimensional scale of perceived social support total scores and friend score (p-value <0.01). Burden score was indirectly proportional to the family, significant other, friend and multidimensional scale of social support total scores (Figure 1). Furthermore, it was discovered that there was a negative moderate significant correlation between brief symptom inventory subscale and global index scores and the family, significant other, friend and multidimensional scale of perceived social support scores (p-value <0.01). Somatization, OCD, depression, anxiety disorder, hostility, phobic anxiety, paranoid ideation, psychoticism, additional items, distress severity index, positive symptom total index and positive symptom distress index were inversely proportional to family, significant other, friend and multidimensional scale of perceived social support total scores (Figure 1).

Discussion

In this study, 48.0% of the patients' relatives providing care were in the age group of 30-49 years, 66.8% were female, 88.5% were married and 24.0% were high school graduates. The studies carried on caregivers, stated that caregivers were mostly married, female, under the age of 50, literate and at least primary school graduate.[10-12] The results were in accordance with that of this study. The reason "why caregiving was perceived as the role of women in the societies" might be because women were considered first in the household chores and child growth processor when adults need care; such as old age and health problems. Furthermore, it was observed that 58.6% of the patients were 65 years old and over, their age average was 65.16±16.98, 53.9% were female, 69.1% were married, 36.8% were literate, 46.1% were insured by Supplemental Security Income (SSI) and the income of 51.6% of them was equal to their expenses. As understood from the results of the related studies,[13,14] it was observed that most of the people receiving service from the HCS unit were over the age of 65 years, which was in accordance with the results of this study.

It was observed that the score of the patients' relatives for burden interview was 25.0±16.09 points. Some studies carried out on care burden have revealed that burden interview total score was low,[15,16] moderate,[17-19] and high.[10,20] However, in this study, it was discovered that the total interview score was low, similar to the first two studies. This result might be because it was carried out among the patients' relatives that received service from the HCS unit and were supported by this unit anytime needed.

This study stated that the total score of the patients' relatives for the multidimensional scale of perceived social support was 71.63±18.37. The scores were 24.01±6.07, 24.11±6.26 and 23.52±6.82 points in the family, significant other and friend subscales, respectively. The total score average of the multidimensional perceived social support scale was found to be 53.93±19.24 in the study conducted by Tarı Selçuk and Avcı,[19] in 2016 and 57.01±11.62 in the study conducted by Çiçek,[21] in 2014. Contradict to these studies about caregivers, it was observed that the perceived social support level by the caregivers was high, which supports the results of the current study.[16,22-24] Those differences might occur because of the cultural gap since the studies were carried out in different cities.

	Care Burden	Somatization	Obsessive-Compulsive Disorder	Interpersonal Sensitivity	Depression	Anxiety	Hostility	Phobic Anxiety	Paranoid Ideation	Psychoticism	Additional Items	Distress Severity Index	Symptom Total Index	Symptom Distress Index	Family	Significant Other	Friend	Multidimensional Scale of Perceived Social Support -Total
Care Burden	1.000																	
Somatization	0.396**	1.000																
Obsessive-Compulsive Disorder	0.402**	0.833**	1.000															
Interpersonal Sensitivity	0.402**	0.749**	0.682**	1.000														
Depression	0.360**	0.811**	0.831**	0.712**	1.000													
Anxiety	0.453**	0.802**	0.766**	0.711**	0.797**	1.000												
Hostility	0.358**	0.755**	0.767**	0.693**	0.759**	0.812**	1.000											
Phobic Anxiety	0.332**	0.737**	0.719**	0.652**	0.711**	0.677**	0.707**	1.000										
Paranoid Ideation	0.395**	0.752**	0.757**	0.673**	0.757**	0.768**	0.703**	0.656**	1.000									
Psychoticism	0.393**	0.756**	0.759**	0.722**	0.782**	0.759**	0.749**	0.768**	0.717**	1.000								
Additional Items	0.388**	0.739**	0.748**	0.627**	0.738**	0.782**	0.768**	0.669**	0.748**	0.738**	1.000							
Distress Severity Index	0.438**	0.880**	0.903**	0.802**	0.901**	0.897**	0.880**	0.816**	0.864**	0.872**	0.857**	1.000						
Symptom Total Index	0.410**	0.896**	0.880**	0.798**	0.888**	0.867**	0.856**	0.832**	0.835**	0.872**	0.827**	0.974**	1.000					
Symptom Distress Index	0.339**	0.595**	0.648**	0.529**	0.574**	0.634**	0.606**	0.462**	0.651**	0.517**	0.585**	0.680**	0.533**	1.000				
Family	-0.290**	-0.378**	-0.387**	-0.334**	-0.413**	-0.457**	-0.434**	-0.403**	-0.353**	-0.390**	-0.422**	-0.455**	-0.417**	-0.399**	1.000			
Significant Other	-0.235**	-0.318**	-0.327**	-0.255**	-0.355**	-0.425**	-0.371**	-0.317**	-0.305**	-0.327**	-0.366**	-0.383**	-0.359**	-0.322**	0.840**	1.000		
Friend	-0.311**	-0.430**	-0.431**	-0.407**	-0.467**	-0.491**	-0.468**	-0.410**	-0.400**	-0.435**	-0.439**	-0.509**	-0.468**	-0.392**	0.825**	0.768**	1.000	
Multidimensional Scale of Perceived Social Support -Total	-0.297**	-0.407**	-0.413**	-0.369**	-0.440**	-0.495**	-0.453**	-0.408**	-0.387**	-0.414**	-0.435**	-0.488**	-0.446**	-0.409**	0.941**	0.900**	0.927**	1.000

** p-value<0.01

Figure 1. Examining the Relationship between Care Burden, Multidimensional Perceived Social Support Scale, Short Symptom Inventory and Sub-Dimensions

In this study, a positive moderate significant correlation was discovered between burden score and brief symptom inventory subscales and global indices. Öksüz, et al.,[25] stated in their study that there was a significant positive correlation between burden interview mean scores of the caregivers and their somatization, OCD, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, additional items, distress severity index and positive symptom distress index mean scores. The results of this study shared similar things with Öksüz, et al.,[25] as the care burden increased in people providing care, mental problems also increased. In this study, negative weak correlation was discovered between the burden score and the family, significant other and multidimensional scale of perceived social support total scores. The previous studies also stated that there was a negative correlation between the multidimensional scale of perceived social support and care burden. In addition, the increasing score of the multidimensional scale of perceived social support was a factor decreasing the care burden.[19,22,23] The increase in the multidimensional scale of perceived social support total score and the subscale scores appeared to be associated with the decrease of care burden level.

Furthermore, it was discovered that the correlations of the brief symptom inventory subscale scores and multidimensional scale of perceived social support total score, and the subscale scores were significant. It was observed that there was a negative, moderate correlation between somatization, OCD, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism, additional items, distress severity index, symptom total index and symptom distress index scores, which were there—among the brief symptom inventory subscales and the family, significant other, friend multidimensional scale of perceived social support scores. The study by Dökmen,[22] stated that the correlations between social support total score and family subscale score and the brief symptom inventory subscale scores were significant. In addition, a decrease was observed in the negative mental health symptoms, especially in the caregivers that perceived family support as high. The results stating the positiveness of the correlation between social support and mental health situation were supported by the previous studies.[22,26]

Conclusion

This study discovered that the patients' relatives obtained the highest and lowest scores from the somatization subscale of the brief symptom inventory and the additional items subscale, respectively. Furthermore, the patients' relatives obtained the highest score from the significant other subscales of the multidimensional scale of perceived social support and those that had a mild burden. As the perceived social support level in patients' relatives increased, the care burden and mental health problems decreased. However, this study has a limitation which the care burden and social support needs of caregivers of the patients that received service from the HCS unit are limited in Turkey. The authors may recommend holding a similar study with larger sample groups and

establishing the units to provide support especially according to the results of the brief symptom inventory.

Abbreviations

HCS: Home Care Services, BI: Burden Interview, BSI: Brief Symptom Inventory, OCD: Obsessive-Compulsive Disorder; MSPSS: Multidimensional Scale of Perceived Social Support, COPD: Chronic Obstructive Pulmonary Disease; SSI: Supplemental Security Income.

Ethics Approval and Consent to Participate

This study was approved by Erciyes University Clinical Trials Ethics Committee (Ethics No: 2016/535). Furthermore, the written institutional approval was received from T.R Ministry of Health, General Directorate of Public Hospitals, Niğde Provincial Directorate of Health, Niğde Training and Research Hospital. All study participants provided verbal informed consent before participating in the survey.

Competing Interest

The authors declare that there are no significant competing financial, professional, or personal interests that might have affected the performance.

Availability of Data and Materials

The data are not publicly available owing to their containing information that could compromise the study' participant privacy and consent. However, the data which supported the results of this study were made available by the first author upon reasonable request.

Authors' Contribution

MŞT and EB were involved in the design of the study, where MŞT took on the task of collecting, analyzing, interpreting and writing the data for this study. Meanwhile, EB outlined the study and supervised the data analysis. All authors read and approved the final manuscript.

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