

INFLUENCE OF CARE BURDEN-RELATED FACTORS ON MENTAL HEALTH AND QUALITY OF LIFE OF THE CAREGIVERS OF DEMENTIA PATIENTS

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ABSTRACT

Purpose: The emergence of age-related physical, cognitive and functional losses bring about the need for constant care and rehabilitation of the elderly. This study was conducted with the aim of investigating the care burden of the caregivers of dementia patients and the influencing factors.

Material and Methods: This cross-sectional study was conducted with 152 primary caregivers of dementia patients registered to Health Sciences University Adana Numune and Training Hospital Home Care Services. Data were collected by using a socio-demographic form, the Care Burden Inventory, the Hospital Anxiety and Depression Scale, and the Short Version of the Quality of Life Assessment Instrument from the World Health Organization.

Results: Of the participants, 66.4% (n=101) had high care burden. While 75.7% of the caregivers did not have anxiety risk, 71.7 had depression risk. While anxiety and depression scale scores significantly increased, quality of life scores were significantly lower in the caregivers who had care burden risk.

Conclusion: Dementia leads to a severe care burden for the caregivers with the increasing dependency of the patients. The establishment of hospice care institutions would improve the care of the patients and the quality of life of the caregivers.

Keywords: Dementia, caregiver, care burden

INTRODUCTION

The emergence of age-related physical, cognitive and functional losses together with the increase in chronic diseases and related disabilities bring about the need for constant care and rehabilitation of the elderly. The importance of home care services has increased due to the high costs of long-term hospital care and switching to “patient-centered” health care services instead of “clinical-oriented” services (1,2).

Home care services are defined as “providing the health and social services professionally (formal) or by family members and caregivers (informal) at the

home of the individual and in his/her own environment” (3,4). Family caregivers were shown to intensively experience emotional, social, and economic problems. “Caregiver burden” is defined as the physical and psycho-social reactions given when providing care service. Detection of caregiver burden and the related factors would enable to improve the quality of life and provide better care (5,6).

Dementia which is among the most common diseases that require home care services shows a progressive course with cognitive and functional losses in the elderly and thereby leads to a great

burden for the caregivers. Depression and anxiety were reported to be more common among the caregivers of dementia patients as compared to the general population (7). Care burden increases with the increasing dependency of the patient, particularly in advanced stages and the quality of life of the caregivers is impaired. Caregivers may receive professional care support or the patients may be treated in institutions that provide inpatient care for reducing the caregiver burden (8).

The present study was conducted to investigate the care burden of the caregivers of dementia patients who were being followed up by home care services and the influencing factors, and the relationship between the anxiety-depression risk and quality of life.

MATERIAL AND METHODS

This cross-sectional study was conducted with 152 primary caregivers of dementia patients registered to Health Sciences University Adana Numune Research and Training Hospital Home Care Services. The subjects have been providing care for at least 6 months. Socio-demographic characteristics of the caregivers and various factors that influence care burden were questioned through a structured questionnaire form with face-to-face interviews. Care burden was evaluated by using the Care Burden Inventory (CBI), anxiety and depression were evaluated by using the Hospital Anxiety and Depression Scale (HADS), and quality of life of the caregivers was evaluated by using the Short Version of the Quality of Life Assessment Instrument from the World Health Organization" (WHOQOL-BREF).

Care Burden Inventory (CBI)

The Care Burden Inventory was developed by Novak and Guest for measuring the care burden of the caregivers and includes 24 items. It is composed of 5 sub-factors based on the fact that the burden is multi-dimensional. The overall scores vary between 0 and 100, and while the scores 24 and above indicate that the caregiver needs support, the scores 36 and above indicate an increased care burden risk, higher scores indicate higher burden and lower scores indicate lower burden (9). Turkish validity and reliability of the inventory was studied by Küçükgülü et al. (10).

Hospital Anxiety and Depression Scale (HADS)

The 14-item scale is applied to subjects with somatic diseases and who apply to primary care services to

detect anxiety and depression risk and their level. It is a self-report scale consisting of two subscales, one measuring anxiety with seven items (HADS-A) and one measuring depression with seven items (HADS-D). The subject gives answers to each question on a 4-point (0–3) Likert scale and answering how he/she has been feeling in the past week. Items 1, 3, 5, 7, 9, 11, 13 belong to the anxiety subscale, while items: 2, 4, 6, 8, 10, 12, 14 belong to the depression subscale. The total score is obtained by summing the scores within each subscale. The score 0–7 represents "normal," 8–10 "mild," 11–14 "moderate," and 15–21 "severe." In the present study, the cut-off score of ≥ 8 and of ≥ 11 was used for HADS subscales. Turkish reliability and validity study was conducted by Ömer Aydemir et al. (11,12).

"Short Version of the Quality of Life Assessment Instrument from the World Health Organization" (WHOQOL-BREF)

A total of 4 dimensions including physical, psychological, social relationships, and environment are evaluated with a total of 26 questions. An overall score is not calculated and quality of life is accepted to improve as the score increases. Turkish validity and reliability study of the scale was conducted by Eser et al. (13,14). The Turkish version of the World Health Organization Quality of Life Scale that is protected by the World Health Organization WHOQOL Turkey headquarters was found appropriate for our scientific use by Prof. Eser. Written and verbal informed consent was obtained from the participants. Ethics committee approval was obtained from Adana Numune Research and Training Hospital (date: 19.01.2016/number:12) prior to the study.

Statistical Analyses

Data were analyzed by using the Statistical Package for Social Sciences version 16.0 (SPSS 16.0) program. Descriptive statistics were done for the socio-demographic characteristics of the caregivers and for dementia patients who receive care. Normality distribution was tested with the Kolmogorov-Smirnov test. For normally distributed variables, two independent variables were tested by using Student's t-test, the Kruskal-Wallis test was used for non-normally distributed variables, and categorical variables were tested by using chi-square tests. A p level of <0.05 was accepted as statistically significant.

Table 1. Caregiver characteristics of the participants and disease status of the dementia patients

Socio-demographic characteristics of the caregivers (N=152)		N (%)
Staying in the same house with the patients	Yes	117 (77.0)
	No	35 (23)
Someone else also helps for caregiving	Yes	68 (44.7)
	No	84 (55.3)
Receiving caregiver wage from the government	Yes	51 (33.6)
	No	101 (66.4)
Having another work	Yes	21 (13.8)
	No	131 (86.2)
Having an experience in caregiving	Yes	22 (14.5)
	No	130 (85.5)
Receiving money for caregiving	Yes	19 (12.5)
	No	133 (87.5)
Disease status of the dementia patients (N=152)		N (%)
Dementia stage	Early	15(9.9)
	Intermediate	67(44.1)
	Advanced	70(46.1)
Co-morbid conditions	Yes	130(85.5)
	No	22(14.5)
Presence of pressure ulcer	Yes	47(30.9)
	No	105(69.1)
Nutrition type	Per-oral without help	35(23)
	Per-oral with help	98(64.5)
	With NG or PEG tube	19(12.5)

NG: Naso-gastric, PEG: Percutaneous endoscopic gastrostomy

RESULTS

The mean age of 152 participants was 49.4±9.0 years (min 30- max 75). Of the participants, 121 (79.6%) were females and 31 (20.4%) were single, divorced, or widowed. Of the caregivers, 15 (9.9%) were illiterate, 83 (54.5%) were graduates of elementary/secondary school and 54 (35.5%) were graduates of the university. The mean age of the patients was 79.8±8.0 years (min 55- max 92), of them, 84 (55.2%) were females, 90(59.2%) were illiterate, 46 (30.3%) were graduates of elementary/secondary school and 16 (10.5%) were graduates of the high school/university.

Caregiver characteristics of the participants and disease status of dementia patients are presented in Table 1.

The mean care burden score of the caregivers was 41.9±14.7 according to CBI. According to the scale, 66.4% (n=101) were found to have high care burden. When the scores were estimated according to subscales, the mean score was 16.7±3.4 for “time-dependent burden”, 10.0±4.6 for “developmental burden”, 7.5±4.1 for “physical burden”, 5.1±3.9 for “social burden”, and 2.5±3.1 for “emotional burden”.

According to the HAD scale, the mean score was 7.9±3.9 for anxiety risk and 9.7±4.4 for depression risk. While 75.7% (n=115) of the caregivers were found not to have anxiety risk, 71.7(n=109) were found to have depression risk according to the HAD-A and HAD-D scale scores.

The mean score of the WHOQL-Bref was 48.8±8.8. Mean scores for “bodily field”, “spiritual field”, “social field” and “environmental field” were found to be 11.8±2.8, 12.3±2.7, 12.2±3.0 and 12.3±1.9, respectively.

When the influence of socio-demographic characteristics of the caregivers and the patients on the CBI score was analyzed, the mean CBI score of the caregivers who were graduates of high school/university (37.8±14.4) was found to be significantly lower as compared to the illiterate (44.0±14.9) and graduates of elementary/secondary school (44.2±14.4) ($\chi^2=6.891$, $p=0.032$) (Table 2).

When the influence of care burden-related factors of the caregivers and the patients on CBI, HAD-A, HAD-D and WHOQOL-Bref scores were evaluated, CBI scores of the caregivers who received help from the other family members were significantly higher than those who did not receive help (42.5±13.3 vs 41.5±15.8, $p=0.030$). The HAD-D score was significantly higher in the caregivers who received help as compared to the caregivers who did not receive help (10.5±4.6 vs 9.07±4.2, $p=0.048$) and the mean WHOQOL-Bref score was significantly lower in the caregivers who received help as compared to the caregivers who did not receive help (47.8±8.7 vs 49.7±8.8, $p=0.001$) (Table 3).

The mean CBI (38.8±14.3 vs 43.5±14.7, $p=0.020$) and HAD-A scores (6.9±3.8 vs 8.4±3.8, $p=0.009$) were significantly lower and the mean WHOQOL-Bref score (50.3±8.2 vs 45.1±9.0, $p=0.01$) was significantly higher in the caregivers who received wage as government assistance as compared to the ones who did not receive (Table 3).

Table 2. The influence of socio-demographic characteristics of the caregivers and the patients on Care Burden Inventory score

N=152		CBI*(Mean ±SD)	Test **	p
Gender of the caregiver	Male (N=31)	42.1±18.7	t=0.093	0.926
	Female (N=121)	41.9±13.6		
Marital status of the caregiver	Married (N=121)	41.4±14.1	T=0.958	0.392
	Single/Divorced/Widowed (N=31)	44.0±16.9		
Educational status of the caregiver	Illiterate (N=15)	44.0±14.9	$\chi^2=6.891$	0.032[†]
	Elementary/Secondary school (N=83)	44.2±14.4		
	High school/University (N=54)	37.8±14.4		
Gender of the patient	Male (N=68)	42.0±14.0	t=0.086	0.932
	Female (N=84)	41.8±15.3		
Marital status of the patient	Married (N=63)	42.1±16.9	t=0.108	0.914
	Single/Divorced/Widowed (N=89)	41.8±13.0		
Educational status of the patient	Illiterate (N=90)	42.2±15.7	$\chi^2=0.285$	0.867
	Elementary/Secondary school (N=46)	42.3±13.4		
	High school/University (N=16)	39.5±12.5		

*CBI: Care Burden Inventory, ** Student t and Kruskal Wallis tests were used, † p<0.05

The mean CBI (32.5±15.0 vs 43.4±14.1, p=0.002) and HAD-A scores (6.3±3.0 vs 8.2±3.9, p=0.041) were significantly lower among the caregivers who had an additional work. The mean CBI score was significantly lower (39.3±14.0 vs 42.3±14.8, p=0.021) and the mean WHOQOL-Bref score was significantly higher (54.4±9.8 vs 48.0±8.4, p=0.003) in the caregivers who were receiving payment for patient care as compared to the ones who were not receiving money for patient care (Table 3).

While the presence of co-morbid conditions did not lead to a significant difference in scale scores of the caregivers, the mean HAD-A score (9.2±3.7 vs 7.3±3.9, p=0.007) and HAD-D score (11.4±4.2 vs 8.9±4.3, p=0.002) were significantly higher and the mean WHOQOL-Bref score was significantly lower (45.4±8.4 vs 50.4±8.5, p=0.001) in the caregivers who were giving care for the patients with a pressure ulcer as compared to the ones who were giving care for the patients without a pressure ulcer (Table 3).

While the mean CBI score was seen to show a linear by linear association as dementia stage increased (early stage: 34.0±19.7, intermediate stage: 40.6±14.1 and advanced stage: 45.0±13.3, p=0.005), HAD-A (8.4±4.0 vs 8.0±4.5 and 7.4±3.7, p=0.042) and HAD-D scores (10.7±4.6 vs 9.3±4.3 and 8.7±4.2, p=0.030) were seen to be significantly higher in advanced stage as compared to early-stage and intermediate stage (Table 3). The mean WHOQOL-Bref score linearly decreased as dementia stage

increased (early stage: 52.3±8.3, moderate stage: 50.1±5 and advanced stage: 46.9±8, p=0.009).

The mean CBI score showed a linear by the linear association according to the nutrition type of the patient (per-oral without help: 37.4±16.0, per-oral with help: 42.2±14.6, through NG or PEG tube: 48.7±9.9, p=0.008). Similarly, HAD-A (6.7±4.6 vs 8.0±3.6 and 9.8±3.4, p=0.003) and HAD-D scores (8.3±4.5 vs 10.5±4.6 and 10.5±3.2, p=0.050) showed a linear by the linear association in caregivers of the patients who were fed per-orally without help as compared to the caregivers of the patients who were fed per-orally with help and through NG/PEG tube. The mean WHOQOL-Bref score significantly decreased by a linear association as nutrition type changed (per-oral without help: 50.4±7.9, per-oral with help: 49.5±9.0, through NG or PEG tube: 42.4±6.4, p=0.002) (Table 3).

The HAD-A, HAD-D and WHOQOL-Bref scores were compared according to care burden risks. While anxiety and depression scale scores significantly increased, WHOQOL-Bref scores were found to be significantly lower in the caregivers who had a care burden risk as compared to the ones who did not have a care burden risk, and in the caregivers who had a high care burden risk (Table 4).

DISCUSSION

The present study has revealed that the vast majority of the caregivers were females, had high care

burdens, and increased anxiety and depression risk. Receiving wages from the government for caregiving decreased care burden, anxiety and depression risk, and improved quality of life. On the other hand, the presence of pressure ulcers, an advanced dementia stage, feeding with help or through NG/PEG tube were found to increase care burden, anxiety, and depression risk and impair the quality of life. The anxiety and depression risk also increased, and quality of life was impaired as the care burden of the caregivers has increased.

the same house with the elderly subjects (16). Women were reported to perceive caregiving as the continuity of their roles and responsibilities within the family, and men were reported not to be familiar with caregiving (17). In our country, most dementia patients receive care in their homes and the women of the family usually take the responsibility for caregiving. In a study conducted with the primary caregivers of the home care patients, 78% of the caregivers were found to be females and 34% were found to give care to their spouses (18). Of dementia

Table 3. The influence of care burden-related factors of the caregivers and the patients on CBI, HAD-A, HAD-D and WHOQOL-Bref scores

N=152	CBI ^I		HAD-A ^{II}		HAD-D ^{III}		WHOQOL-Bref ^{IV}	
	χ^2	p	χ^2	p	χ^2	p	χ^2	p
Staying in the same house with the patients	66.102	0.167	19.215	0.315	20.654	0.418	152.94	0.289
Someone else also helps for care giving	77.456	0.030[†]	19.318	0.311	3.908	0.048[†]	200.71	0.001^{††}
Receiving caregiver wage from the government	79.701	0.020[†]	33.711	0.009^{††}	6.334	0.012[†]	185.64	0.011[†]
Having another work	10.041	0.002^{††}	4.160	0.041[†]	22.034	0.339	119.31	0.934
Having an experience in care giving	40.496	0.941	17.755	0.404	22.864	0.296	122.92	0.898
Receiving payment for care giving	79.467	0.021[†]	22.845	0.154	21.088	0.392	8.745	0.003^{††}
Presence of co-morbid conditions	64.814	0.196	13.346	0.713	19.058	0.518	117.37	0.949
Presence of pressure ulcer	63.400	0.232	7.248*	0.007^{††}	9.668*	0.002^{††}	10.604*	0.001^{††}
Dementia stage ^a	7.787*	0.005^{††}	49.346	0.042[†]	4.733*	0.030[†]	6.817*	0.009^{††}
Nutrition type ^b	7.089*	0.008^{††}	8.528*	0.003^{††}	5.746*	0.050[†]	9.259*	0.002^{††}

^aDementia stage: 1. Early stage, 2: Intermediate stage, 3: Advanced stage

^bNutrition type: 1. Per-orally without help, 2. Per-orally with help, 3. Through naso-gatric or percutaneous gastrostomy tube

^ICBI: Care Burden Inventory, ^{II}HAD-A: Hospital Anxiety and Depression Scale, ^{III}HAD-D: Hospital Anxiety and Depression Scale ^{IV}WHOQOL-BREF: Short Version of the Quality of Life Assessment Instrument from the World Health Organization

The elderly population increases in our country as in the whole world. Dementia which is characterized by cognitive dysfunction comes into the foreground in old age as an important public health problem. The care burden of dementia patients who gradually need more help for daily living activities and lose their independence influences the whole family (15). A study conducted in the USA for investigating the profile of the informal caregivers of susceptible elderly has revealed that the vast majority of the caregivers were females and of them, three-fourth were living in

patients who were being followed up at the neurology clinic of a private university hospital, 68.8% of the caregivers were found to be females. In the study, the mean CBI scores of the family caregivers were 31.9 indicating a moderate care burden. The mean CBI scores were also found not to show a statistically significant difference according to gender, age, educational status, and economic status of the participants (p>0.05) (19). The mean CBI scores of female caregivers were found to be significantly higher than those of male caregivers (31.8±21.6 vs

Table 4. Comparison of care burden risk and anxiety, depression and quality of life scores of the caregivers

Scale	Care burden risk			χ^2 *	p
	No (n=15)	Yes (n=36)	High (n=101)		
CBI	16.4±4.8	30.0±3.4	50.0±10.2	104.620	0.000 [†]
HAD-A	3.4±1.9	5.3±3.2	9.5±3.3	54.693	0.000 [†]
HAD-D	5.1±3.7	6.3±3.6	11.5±3.5	52.659	0.000 [†]
WHOQOL-Bref	59.8±4.9	53.8±7.7	45.9±7.4	47.995	0.000 [†]

^ICBI: Care Burden Inventory, ^{II}HAD-A: Hospital Anxiety and Depression Scale, ^{III}HAD-D: Hospital Anxiety and Depression Scale ^{IV}WHOQOL-BREF: Short Version of the Quality of Life Assessment Instrument from the World Health Organization

*Kruskal Wallis Test, [†]p<0.001

24.0±21.3, p=0.010) of 305 dementia patients who were being followed up at neurology clinics of university and state hospitals in İzmir (20). The vast majority of the caregivers of dementia patients were females (79.6%) and 20.4% were males also in our study, and 77.0% were living in the same house with the patient. The mean CBI score of the caregivers was 41.9±14.7 and the care burden was high (>36) in 101 caregivers (66.4%). In the comparison of the socio-demographic characteristics of the caregivers and the patients, the mean CBI score was found to significantly decrease with only the increased educational status of the caregiver.

Previous studies showed a high mental disorder risk among the caregivers of the elderly with dementia. In the study by Dura et al. conducted with 78 adults who were giving care to their parents with dementia, while anxiety disorder was detected in 8 subjects (10.2%), it was found in only one subject (1.2%) in the control group. While 14 subjects (17.9%) had depressive disorder, no subjects in the control group had depressive disorder (21). The mean HAD-A score was found to be 10.4±4.2 and the mean HAD-D score was found to be 8.0±4.0 in caregivers of 30 patients who had Alzheimer's disease in the study by Ostojic et al. from Croatia. The ratio of anxiety was 46.7% and depression was 26.7% in that study (22). The mean HAD-A score was 7 to 3.9 and the mean HAD-D score was 9.7±4.4 in our study indicating a high risk for both. According to these results, anxiety risk was 24.3% (HAD-A score>11) and depression risk was 71.7% (HAD-D score>8) in 152 caregivers.

In our country, the government pays wages to the caregivers who give home care to the elderly. In the present study, the ratio of caregivers who were receiving government assistance was 66.4%. Care burden, anxiety and depression risks were found to be lower and quality of life was found to be higher

among the caregivers who were receiving government assistance.

Caregiving a dementia patient is challenging on several counts. The disease course has seven stages beginning from very mild cognitive impairment (Stage 1) to very severe cognitive impairment (late-stage dementia) (Stage 7). Due to the progressive nature of the disease, the social and motor skills of the patients in later stages are impaired more and they need substantial care for daily activities. As the disease stage increases, the care burden increases and the quality of life decreases (8, 23). While advancement to another stage is a trauma for the caregivers as signs and symptoms progress with disease stage, the advanced stage is the most important with regard to the responsibilities of the caregiver as the patient cannot maintain daily living activities without help. As patient dependence increases, caregivers' morbidities including depression, impaired quality of life, immune suppression, and increased cortisol levels may increase leading to the early institutionalization of the patient (24,25,26). The results of our study also support these findings.

Gender, marital or educational statuses of the patients were found not to affect care burden of the caregiver in our study. Caregivers may provide professional support or admit to an inpatient institution for the care of the patient. These issues are challenging in our country due to the insufficiency of professional care systems, professional health staff, and economic difficulties. While hospice care that provides palliative care to individuals in their terminal period and enables dying with dignity is more common in developed countries, hospice care institutions are not available in our country although palliative care and home care services have become widespread (27). A randomized clinical trial with 634 dementia patients found that dementia care

management may significantly improve the outcomes of treatment and care among people with dementia, and caregiver burden should be incorporated into routine care (28). Vladimir Khanassov et al. have reported that caregivers of dementia patients need a contact person, a clear explanation of their dementia diagnosis, a care plan, written information on available services, and support for caregiving (29).

CONCLUSION

Dementia that goes with severe cognitive and functional losses and requires home care is among the most common chronic diseases in the elderly and leads to a severe care burden for the caregivers with the increasing dependency of the patients. Our study has once revealed that like the other chronic diseases, particularly severe ones like cancer, psychosis, and dementia should be addressed as the disease of the whole family and not only the patients. The requirements of primary caregivers should also be considered by family physicians. The establishment of hospice care institutions would improve the care of the patients and the quality of life of the caregivers.

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