ORİJİNAL ARAŞTIRMA ORIGINAL RESEARCH

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Life Satisfaction and Care Burden of Caregivers Who Provide Care at Home to Elderly Patients and the Influencing Factors

Yaşlı Hastaya Evde Bakım Verenlerin Yaşam Doyumları ile Bakım Yükleri Arasındaki İlişki ve Etkileyen Faktörler

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This study was presented as a poster at 10th Conference of the Global Network of WHO Collaborating Centres for Nursing and Midwifery, 23-25 July 2014, Coimbra, Portugal.

ABSTRACT Objective: This study aimed to determine the relationship between life satisfaction and care burden in those who provide care to impaired elderly individuals at home and the factors that affect that relationship. **Material and Methods:** This relational descriptive study was conducted between July 2012 and June 2013. The study population comprised 200 caregivers who provided care to elderly individuals (aged 65 years or older) registered with the Home Care Center of Adiyaman University Training and Research Hospital. In total, 160 caregivers participated in this study. Data were collected using a questionnaire prepared by the investigator that included demographic information, the Burden Interview and the Satisfaction with Life Scale. Data were evaluated using the Statistical Program for Social Sciences (SPSS) 16.0 package program. Statistical analysis was used to number, percentage, t-test, ANOVA and correlation. **Results:** The majority of caregivers were women and married. Overall, the caregivers' care burden and life satisfaction were determined at moderate levels (46.45±15.40 score). Factors such as sex, income status and care satisfaction affected care burden, whereas education level and income status affected life satisfaction. A negative correlation was found between care burden and life satisfaction of the caregivers. **Conclusion:** The results of this study demonstrated that the burden of care decreases the life satisfaction. To decrease care burden and increase the life satisfaction of caregivers, national policies and training programmes should be developed.

Keywords: Elderly; caregiver; care burden; life satisfaction; nursing

ÖZET Amaç: Bu araştırmanın amacı yaşlı hastaya evde bakım verenlerin yaşam doyumları ile bakım yükleri arasındaki ilişki ve etkileyen faktörleri belirlemektir. **Gereç ve Yöntemler:** İlişkisel tanımlayıcı olan çalışma Temmuz 2012-Haziran 2013 tarihleri arasında yapıldı. Araştırmanın evrenini, Adıyaman Üniversitesi Eğitim ve Araştırma Hastanesi Evde Bakım Merkezi'ne kayıtlı 65 yaş ve üzeri yaşlı hastaya bakım veren 200 bakım verici oluşturdu. Toplamda 160 bakım veren çalışmaya katıldı. Verilerin toplanmasında araştırmacı tarafından hazırlanan Bakım Veren ve alan Bireyi Tanıtıcı Anket Formu, Bakım Verme Yükü Ölçeği (BYÖ) ve Yaşam Doyumu Ölçeği (YDÖ) kullanıldı. Veriler SPSS 16.0 paket programında değerlendirildi. İstatistiksel analizde sayı, yüzde, t-testi, ANOVA ve korelasyon kullanıldı. **Bulgular:** Bakım verenlerin çoğunluğu kadın ve evliydi. Katılımcıların bakım yükü ve yaşam doyumunun orta düzeyde olduğu belirlendi (46.45±15.40 puan). Cinsiyet, gelir düzeyi ve bakım vermekten memnuniyet gibi faktörler bakım yükünü etkilerken, eğitim düzeyi ve gelir durumu yaşam doyumunu etkilediği saptandı. Bakım vericilerin bakım yükü ile yaşam doyumları arasında negatif ilişki bulundu. **Sonuç:** Bu araştırmanın sonuçları bakım vericilerin bakım yükünün, yaşam doyumunu azalttığını göstermektedir. Bu nedenle bakım verenlerin bakım yükünü azaltmak ve yaşam doyumunu arttırmak için, ulusal politikalar ve eğitim programları geliştirilmelidir.

Anahtar Kelimeler: Yaşlı; bakım verici; bakım yükü; yaşam doyumu; hemşirelik

The world's population is ageing. Factors such as scientific and technological developments in medicine, disease prevention, early diagnosis and treatment, development of protective healthcare services, decreasing fertility rates and infant mortality are among the reasons for the increase in the elderly population.[1-3]

In 2015, the world population over the age of 65 was estimated at 8.5; and is predicted to rise to 16.7 % by 2050.[4] According to Turkish Statistical Institute data elderly individuals aged over 65 years constitute 7.8% of Turkey's total population.[5] With this rapid increase in the elderly population globally, some problems specific to the elderly individuals have emerged.[6] Caring problems and the needs of caregivers are among the most common. Family members often assume an important role in looking after impaired older individuals, and this role of caregivers has become more difficult in changing cultural and economic environments.[7] Providing care affects the physical, emotional, social and financial status of caregivers.[8] Stenberg et al. found that the most prevalent physical problems reported by caregivers included sleep disturbance, fatigue, pain, loss of physical strength, loss of appetite, and weight loss.[9] Lambert et al. found that more than one third of caregivers reported borderline or clinical levels of anxiety.[10]

Care burden is affected by variables such as the caregiver's age and sex, their physical and psychological health, the relationship between the impaired person and the caregiver, time spent on providing care and the dependency status of the care recipient.[11,12] Caregivers who did not experience difficulties during the process of giving care were less affected by the negative aspects of caregiving, and their life satisfaction improved when they received attention and support from their families, friends and healthcare professionals.[13] However, when a caregiver's burden increases, their life satisfaction decreases.[13] Ho et al. found that caregiver burden score was inversely associated with quality of life.[14]

Increased caregiver burden negatively affects life satisfaction. Therefore, determining the relationship between care burden and life satisfaction and identifying factors that affect this relationship are important when planning nursing care. The purpose of this study was to determine the relationship between life satisfaction and care burden of caregivers who provide care at home to impaired elderly individuals and investigate the factors affecting that relationship.

MATERIAL AND METHODS

STUDY DESIGN AND SETTING

The study used a relational descriptive design and was conducted between July 2012 and June 2013. Participants were caregivers who provided care to elderly individuals who are registered with the Home Care Center of the Adiyaman University Training and Research Hospital in the provincial center of Adiyaman, Turkey. Because we aimed to include the entire caregiver population (n= 200) in the study, we did not calculate the sample size and did not use any sampling method. In total, 160 caregivers who provided care to an impaired elderly individual were included in this study, representing 80% of the target population inclusion criteria were as follows: (i) caregivers who were able to speak Turkish, (ii) were living with the elderly care recipient and (iii) had kinship with the elderly care recipient (those who were paid to provide care were excluded).

Data were collected by the investigator through face-to-face interviews with caregivers. Interviews were conducted during patient visits alongside home care staff who worked 5 days per week. The interviews lasted for approximately 20-25 minutes. A socio-demographic data form comprising 22 questions about the characteristics of the caregiver and the care recipient, the Burden Interview (BI) and the Satisfaction with Life Scale (SWLS) were used during the interviews.

ETHICAL CONSIDERATIONS

Written permission was obtained for the study from the Clinical Trials Ethics Committee in Malatya and the Provincial Health Directorate in Adiyaman. Permission was also obtained from Inci and Erdem, who conducted the validity and reliability for the Turkish version of BI.[15] Before administering the forms, the purpose of the study was explained to the patients and their verbal approvals were obtained; their privacy was respected.

MEASUREMENTS

Burden Interview (BI): This widely used interview was developed by Zarit, Reever and Bach-Peterson in 1980 to assess the difficulties experienced by caregivers. The interview can be completed by the caregivers themselves or the investigator and comprises 22 statements covering the effect of caregiving on the individual's life, with a focus on social and emotional issues (physical, psychological and social well-being). Responses are on a Likert-type scale ranging from 0 to 4 ("never", "rarely", "sometimes", "quite frequently" and "nearly always"). Total scores range from 0 to 88, and higher scores indicate higher levels of difficulty experienced. Scores of 0-20 are assessed as 'little or no burden', 21-40 as "mild to moderate burden", 41-60 as "moderate to severe burden" and 61-88 as "severe burden". The interview has been tested for validity and reliability in many countries, with testing for validity and reliability in Turkish con- ducted by İnci and Erdem. The Cronbach alpha coefficient for the interview ranged from 0.87 to 0.99.[15] The Cronbach alpha coefficient found 0.87 in our study.

Satisfaction with Life (SWLS): This scale, developed by Diener, Emmans, Lorsen and Giffin (1985), consists of five items expressed in the same direction. Responses are on a Likert-type scale ranging from 1 to 7 ('strongly disagree' to 'strongly agree'). The scale is a self-report instrument and can be completed in 5 min. SWLS was translated to Turkish by Koker and showed test–retest reliability of 0.85 and internal consistency of 0.78. The highest obtainable SWLS score is 35 and the lowest possible score is 5; higher scores indicate higher satisfaction with life.[16] The Cronbach alpha coefficient found 0.88 in our study.

DATA ANALYSIS

Data were evaluated using the Statistical Program for Social Sciences (SPSS) 16.0 package program. Socio-demographic data for caregivers and care recipients (impaired elderly individuals) were expressed in numbers and percentages. ANOVA was used to compare age, education level, occupation and family income status with BI and SWLS scores. Correlation analysis was used to identify the relationship between the mean BI and SWLS scores, and t-tests were used to compare sexes by BI and SWLS scores in independent groups. A p-value of <0.05 was considered statistically significant with a 95% confidence interval.

RESULTS

The mean age of caregivers was 48.01 ± 1.60 years; 83.1% were female, 83.8% were married and 41.9% had not graduated from primary school. Most caregivers (88.1%) were not working, 90.6% had social security and 56.9% had less income than their expenses. In addition, 61.2% of caregivers did not have any chronic disease. In terms of relationship to the care recipient, 32.5% of the caregivers were daughters. A majority of caregivers (63.8%) had cared for their relative for 1–5 years; 85% were happy to provide care and 40% received help while providing care. Reasons for providing care to their relative included family responsibility/family ties (70.6%), the absence of an alternative caregiver (22.5%) and an economic contribution from the elderly individual (6.9%) (Table 1).

The mean age of the care recipients was 77.08 ± 7.83 years, 67.5% were female and 32.5% were male. We found that 41.9% of care recipients had not graduated from primary school, 31.9% had a green card and 74.4% had an income. Common chronic disease diagnoses were hypertension (66.2%), diabetes (39.4%), cerebrovascular disease (23.8%) and heart failure (15.6%) (Table 2).

The mean BI score was highest in the group of caregivers aged 20–39 years. This group also had the lowest SWLS scores, but the difference between the groups was not significant ($p>0.05$). Women suffered significantly more caregiving burden than men ($p<0.05$). Factors such as income status and being happy to provide care affected care burden ($p<0.05$). SWLS scores were lower in the group of caregivers with low education levels than in those with high education levels, and the difference between the groups was significant ($p < 0.05$). Caregivers with less income had lower SWLS scores ($p < 0.05$). Factors such as age group, sex and being happy to provide care did not affect SWLS scores ($p > 0.05$) (Table 3).

There was a negative correlation between care burden and satisfaction with life in caregivers; as care burden increased, satisfaction with life decreased (Table 4).

TABLE 1: Socio-demographic characteristics of caregivers (n=160)

Variables	N	%
Age (year)		
20-39	51	31.9
40-59	68	42.5
60 and above	41	25.6
Gender		
Female	133	83.1
Male	27	16.9
Marital Status		
Married	134	83.8
Single	26	16.2
Level of education		
Illiterate	67	41.9
Primary school	49	30.6
Secondary education	34	21.2
University and above	10	6.2
Employment Status		
Working	19	11.9
Not working	141	88.1
Social Security		
Yes	145	90.6
No	15	9.4
Income Status		
Less income than expenses	91	56.9
Income equal to expenses	69	43.1
Chronic Diseases		
Yes	62	38.8
No	98	61.2
Kinship with the Elderly		
Daughter	52	32.5
Spouse	47	29.4
Daughter-in-law	41	25.6
Son	20	12.5
Happy to give care		
Yes	136	85.0
No	24	15.0
Persons giving support for care		
Sister	30	18.8
Spouse	19	11.9
Daughter	15	9.4
Period of giving care		
1-5 years	102	63.8
6-10 years	39	24.4
11 and above years	19	11.9
Reason for giving care to elderly		
Family responsibility / family ties	113	70.6
Absence of anyone else to give care	36	22.5
Economic contribution	11	6.9
Total	**160**	**100.0**

TABLE 2: Socio-demographic characteristics of care recipients (n=160).

Variables	N	%
Age (year)		
65-74	65	40.6
75-84	67	41.9
85 and above	28	17.5
Gender		
Female	108	67.5
Male	52	32.5
Marital Status		
Married	95	59.4
Single	65	40.6
Level of education		
Not primary school	67	41.9
Primary school	49	30.6
Secondary education	44	27.5
Social Security		
Social security institution (SGK)	109	68.1
Green card	51	31.9
Income Status		
Has own income	119	74.4
Has no income	41	25.6
Diagnosis of disease of the elderly		
Hypertension	106	66.2
Diabetes	63	39.4
Cerebrovascular disease	38	23.8
Osteoporosis	25	15.6
Heart failure	24	15.0
Asthma	18	11.2
Mean age (year)		**77.08 ± 7.83**
Total	**160**	**100.0**

DISCUSSION

In their study, Akyar and Akdemir found that 50% of caregivers had provided care to their care recip-

TABLE 3: Comparison of mean scores of burden interview and satisfaction with life of caregivers with socio-demographic characteristics.

Features	Care burden X ± SD	p-value	Satisfaction with life X ± SD	p-value
Age groups (years)				
20-39	49.50±17.41	F:1.513	17.29±5.88	F: 1.242
40-59	44.73±12.27	p: .223	18.80±4.74	p: .292
60 and above	45.51±17.15		17.85±5.39	
Gender				
Female	47.64±15.18	t: 2.195	18.24±5.33	t: .842
Male	40.59±15.43	p: .030	17.29±5.17	p: .401
Level of education				
Not primary school	47.61±13.98		17.02±4.47	
Primary school	47.57±15.32	KW: 3.482	18.28±5.33	KW: 10.391
Secondary education	44.26±17.43	p: .323	18.32±5.91	p: .016
University and above	40.70±17.88		23.30±5.57	
Income status				
Less income than expenses	49.82±15.18	t: 3.271	16.53±5.07	t: -4.469
Income equal to expenses	42.01±14.64	p: .001	20.11±4.93	p: .000
Happy to give care				
Yes	44.30±14.64	MN-U: 743.000	18.45±5.28	MN-U: 1238.500
No	58.62±14.16	p:.000	15.95±5.04	p: .060

F: Anova **t:** t testi **MN-U:** Mann Whitney U **KW:** Kruskall Wallis.

TABLE 4: Relationship between mean scores of care burden and satisfaction with life scale of caregivers.

	Min	Max	X ± SD
Care burden	13.0	88.0	46.45±15.40
Satisfaction with life	5.0	33.0	18.08±5.30
r=-.359**		p=.000	

**p<0.001

ient for 1–5 years, which is consistent with the results of this study.[17] Our finding demonstrated that most caregivers were happy to provide care which might reflect the fact that respect, love and tolerance for elderly individuals are key values of the Turkish culture. We found that the overall caregiver burden was at a moderate level (Table 4), consistent with the findings of Karahan et al.[18] In this study, the group of caregivers aged 20–39 years had a higher care burden and lower satisfaction with life, although this was not significant. The higher care burden in younger caregivers may be because young people are inexperienced in providing care and have more responsibilities in daily life. We also found that women suffered more care burden than men, and this was statistically significant (Table 3), a finding consistent with that of previous studies.[19,20] We investigated caregivers' care burden by education level and found that those who had not graduated from primary school had a higher care burden than other groups, but the difference between the groups was not statistically significant (Table 3). Tabeleao et al. found that care burden decreased as education level increased.[21] Loureiro et al. and Salama et al. also found that those with a lower level of education experienced more care burden, with the difference between groups being statistically significant.[22,23] Our results showed that life satisfaction of caregivers who had not graduated from primary school was lower, and the difference between the groups was statistically significant.

We found that care burden was higher and satisfaction with life was lower in caregivers with less income than their expenses, and the difference between the groups was significant (Table 3). This result is consistent with the result of the study done by Garlo et al. who found that a lower income level was associated with a higher care burden.[24] Caregivers with a low income may have a higher care burden because they struggle to meet the needs of the person they look after. We found that caregivers who were not happy to provide care had a higher care burden than those who were happy to provide care, and the difference between the groups was statistically significant (Table 3). Brinda et al. found that 63.5% of caregivers in their study were unhappy with the function of giving care.[25] Providing care affects the physical, emotional of caregivers. Thus, declining wellbeing of caregivers can lead to be unhappiness. In this study, age and sex were not significantly correlated with being happy to provide care or satisfaction with life. However, we found a negative correlation between care burden and satisfaction with life, and satisfaction with life decreased as care burden increased (Table 4). This finding is consistent with that in the study by Riviera et al. Care burden affects all aspects of life so that it may leads to reduced life satisfaction.[26] Danacı and Koc found that there was a negative and significant relationship between caregiving burden and quality of life.[27]

CONCLUSION

In conclusion, care burden and satisfaction with life were at a moderate level. Sex, income level and happiness with care were significantly correlated with care burden. Education status and income level were significantly correlated with satisfaction with life. These results suggest that support systems should be increased by raising awareness among staff providing home care services to help decrease the care burden and increase life satisfaction in family members who provide care to elderly individuals. In particular, nurses should identify the problems experienced by family members with a high care burden and arrange training programmes to help them to cope with problems. Centres such as day nursing homes and day care units should be opened for impaired elderly individuals, and those who provide institutional-level care should be supported. Training and consultancy programs should be generalized in elderly care. Elderly care, difficulties experienced in care and solution proposals in the fields should be given wide coverage to in the curriculum of health departments.

In line with these results, to reduce care burden and to increase life satisfaction must be provided multidisciplinary approach (physician, nurse, psychologist, occupational therapist etc.) both caregivers and elderly patients. Day care homes should be opened to reduce the burden of care. Problems and solutions proposed in elderly care should be added to the education curriculum.

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Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

All authors contribute equally to this work.

REFERENCES

1. Bahar G, Bahar A, Savaş H. [Elderly and social services for the elderly]. Journal of Firat Health Services 2009;4(12):86-98.
2. Fadiloğlu Ç, Ertem G, Aykar F. Home care in elderly, Home Health and Care. 1. Baskı. Ankara: Göktug Publishing; 2013. p.167-76.
3. Aslan D, Ertem M. Elderly Health: Problems and Solutions. Ankara: Palma Publishing; 2012. p.1-8.
4. Olsen A, Gill MS. Chapter 1. Introduction. Ageing: Lessons from C. Elegans. 1st ed. Switzerland: Springer International Publishing; 2017. p.1-7.
5. Unal C. [Aging index of Turkey's population and the distribution of the potential support rate]. Journal of Hasan Ali Yucel Faculty of Education 2015;12(23):235-49.
6. Karahan A, Güven S. [Homecare for elderly]. Turkish Journal of Geriatrics 2002;5(4):155-9.
7. Atagün MI, Balaban OD, Atagun Z, Elagoz M, Ozpolat AY. [Caregiver burden in chronic diseases]. Current Approaches in Psychiatry 2011;3(3):513-52.
8. Chou K, Chu H, Tseng CL, Lu R. The measurement of caregiver burden. Journal of Medical Sciences 2003;23(2):73-82.
9. Stenberg U, Ruland CM, Miaskowski C. Review of the literature on the effects of caring for a patient with cancer. Psychooncology 2010;19(10):1013-25.
10. Lambert SD, Girgis A, Lecathelinais C, Stacey F. Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. Support Care Cancer 2013;21(1):75-85.
11. Guedes AC, Pereira Mda G. Burden, coping, physical symptoms and psychological morbidity in caregivers of functionally dependent family members. Rev Lat Am Enfermagem 2013;21(4):935-40.
12. Di Mattei VE, Prunas A, Novella L, Marcone A, Cappa SF, Sarno L. The burden of distress in caregivers of elderly demented patients and its relationship with coping strategies. Neurol Sci 2008;29(6):383-9.
13. Dokmen Z. [The relations between mental health and perceived social support of family caregivers]. Journal of Ankara University Institute of Social Science 2012;3(1):3-38.
14. Ho SC, Chan A, Woo J, Chong P, Sham A. Impact of caregiving on health and quality of life: a comparative population-based study of caregivers for elderly persons and noncaregivers. J Gerontol A Biol Sci Med Sci 2009;64(8):873-9.
15. Inci FH, Erdem M. [Validity and reliability of the burden interview and its adaptation to Turkish]. Journal of Anatolia Nursing and Health Sciences 2008;11(4):85-95.
16. Civitci A. The relationships between global life satisfaction and psychological needs in university students. Journal of Social Sciences Institute 2012; 21(2): 321-36.
17. Akyar I, Akdemir N. Strains of caregivers of Alzheimer patients. Hacettepe University Faculty of Health Sciences Nursing Journal 2009;16(3):32-49.
18. Karahan AY, Kucuksen S, Yilmaz H, Salli A, Gungor T, Sahin M. Effects of rehabilitation services on anxiety, depression, care-giving burden and perceived social support of stroke caregivers. Acta Medica (Hradec Kralove) 2014;57(2):68-72.
19. Nardi Ede F, Sawada NO, Santos JL. The association between the functional incapacity of the older adult and the family caregiver's burden. Rev Lat Am Enfermagem 2013;21(5): 1096-103.
20. Papastavrou E, Kalokerinou A, Papacostas SS, Tsangari H, Sourtzi P. Caring for a relative with dementia: family caregiver burden. J Adv Nurs 2007;58(5):446-57.
21. Tabeleão VP, Tomasi E, Quevedo LA. Burden on relatives of people with psychic disorder: levels and associated factors. Rev Psiquiatr Clin 2014;41(3):63-6.
22. Loureiro LSN, Fernandes MGM, Marques S, Nóbrega MML, Rodrigues RAP. Burden in family caregivers of the elderly: prevalence and association with characteristics of the elderly and the caregivers. Rev Esc Enferm USP 2013;47(5):1129-36.
23. Salama RAA. Caregiver burden from caring for impaired elderly: a cross-sectional study in rural Lower Egypt. Indian J Public Health 2012;9(4):8662-9.
24. Garlo K, O'Leary JR, Van Ness PH, Fried TR. Burden in caregivers of older adults with advanced illness. J Am Geriatr Soc 2010;58(12): 2315-22.
25. Brinda EM, Rajkumar AP, Enemark U, Attermann J, Jacob KS. Cost and burden of informal caregiving of dependent older people in a rural Indian community. BMC Health Serv Res 2014;7(14):207.
26. Rivera PA, Elliott TR, Berry JW, Shewchuk RM, Oswald KD, Grant J. Family caregivers of women with physical disabilities. J Clin Psychol Med Settings 2006;13(4):425-34.
27. Danacı E, Koç Z. Caregiving burden and life satisfaction among caregivers of cancer patients admitted to the emergency department. Clin Nurs Res 2017. Doi: 10.1177/1054773817708083. [Epub ahead of print].