

The Investigation of Caregiving Burden and Life Quality of Caregivers Who Care for Cancered Patients

Kanserli Hastalara Bakım Veren Bireylerin Bakım Yükü, Yaşam Kalitesi ve Etkileyen Faktörlerin İncelenmesi

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Abstract

Background: Caring for cancer patients affects both the care burden and quality of life of the caregivers. This study was conducted to determine the care load, quality of life of caregivers who care for cancer patients and the influencing factors.

Materials and Methods: This descriptive research which used the Questionnaire Form, Caregiver Quality of Life Index-Cancer Scale and Zarit Caregiver Burden Scale.160 caregivers who agreed to participate in the study composed the sample. In the analysis of the data, descriptive statistics (number, percentage, mean), Independent Samples t test, Kruskal Wallis test, Mann Whitney U test were used.

Results: The mean total burden interview scale score of caregivers was 32.65±15.14 and the mean total caregiver quality of life index-cancer scalescore was 78.75±16.31. It was found that there was a statistically significant difference between the mean total caregiver burden scores according to gender and marital status (p<0.05). There were statistically significant differences between the mean total caregiver burden scores according to the negative affection status of health during caregiving and the mean total life quality scores according to the income status (p<0.05).

Conclusions: It was determined that the individuals providing care had a mild level of care burden and their quality of life was not at the desired level. For this reason, it may be suggested to carry out the care burden at the desired level and to conduct interventional nursing studies to improve the quality of life.

Key Words: Cancer, Care burden, Quality of life, Nursing.

Öz.

Amaç: Kanserli hastaya bakım vermek, bakım vericilerin hem bakım yüklerini hem de yaşam kalitesini etkilemektedir. Bu çalışma, kanser hastalarına bakım verenlerin bakım yükü, yaşam kalitesi ve etkileyen faktörleri belirlemek amacıyla yapılmıştır.

Materyal ve Metod: Tanımlayıcı tipte olan çalışmada, Anket Formu, Kanserli Hastalara Bakım Verenlerde Yaşam Kalitesi Ölçeği ve Zarit Bakım Verme Yükü Ölçeği kullanılmıştır. Çalışmanın örneklemini 160 bakım veren oluşturmuştur. Verilerin analizinde tanımlayıcı istatistikler (sayı, yüzde, ortalama), bağımsız gruplarda t testi, Kruskal Wallis testi, Mann Whitney U testi yapılmıştır.

Bulgular: Bakım veren bireylerin bakım verme yükü ölçeği toplam puan ortalamaları 32.65 ± 15.14, yaşam kalitesi ölçeği toplam puan ortalamaları ise 78.75 ± 16.31'dir. Hasta bireylerin cinsiyet ve medeni durumuna göre bakım verme yükü toplam puan ortalamaları arasında anlamlı bir fark saptanmıştır (p<0.05). Bakım verirken sağlığın olumsuz etkilenme durumuna göre bakım verme yükü toplam puan ortalamaları ve gelir durumuna göre yaşam kalitesi toplam puan ortalamaları arasında istatistiksel olarak anlamlı bir fark saptanmıştır (p<0.05).

Sonuç: Çalışmada bakım veren bireylerin hafif düzeyde bakım yükünün olduğu ve yaşam kalitesinin istenen düzeyde olmadığı saptanmıştır. Bu nedenle bakım yükünün istendik düzeyde devam etmesi ve yaşam kalitesini yükseltmeye yönelik girişimsel hemşirelik çalışmalarının yapılması önerilebilir.

Anahtar kelimeler: Kanser, Bakım yükü, Yaşam kalitesi, Hemşirelik

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Introduction

In developed and developing countries, cancer is an important public health problem which has a dramatically increasing incidence. It is the second most common cause of death after heart diseases in Turkey and in the World (1). The rapidly increasing number of cancer cases, the development of diagnosis and treatment methods, and the prolongation of the lifespan of patients cause the family members to have a primary role in care process and patients to take more responsibility in care (2,3). Therefore, care burden of caregivers increases while their life quality decreases because cancer can affect the psychological health, economic, physical and social status of the family members who care with the patient negatively due to disease process, problems related to the treatment, and high cost (4).

In the studies, it was stated that there are many factors that affect the care burden and life quality of individuals who provide care for cancer patients (5-7). Orak and Sezgin (7) found that the education level, gender and duration of caregiving which are among the factors affecting the care burden of individuals providing care to the patients with cancer (7). In another study, it was stated that caregivers with low education level had more emotional distress, their lives were affected more and their health burdens were worse compared to caregivers with their higher education level (5). In the study of Karabuğa and Pınar, the gender of the caregiver, the gender of the patient, the presence of other caregivers in the family, economical status, old age and inability to fulfill their responsibilities, severe deterioration in physical health due to providing long-term care, anxiety, depression were found as the reasons affecting the quality of life in the family members providing care for the patient (6). In the studies, it was found that caregivers who have difficulties in fulfilling their responsibilities and who do not receive support from other family members have decreased life quality (4,5,8,9). Nursing services play an important role in reducing the burden of care and improving the quality of life of individuals providing care for cancer patients. While patients and their caregivers struggle with a difficult disease, the need for nurses increases (10). In a study conducted by Aktaş et al. (11) it was suggested that it is very important that nurses are in cooperation with the family members providing care and benefit from their support and it is also important that nurses provide consultancy about the time and place of the guidance and assistance services the caregiver needs. It is also beneficial that nurses provide feedback to caregiving family members that their feelings are normal and they do their best, divide the problems experiencing by caregiving family members into resolvable parts and help them to identify the resources and appropriate options (11).

In conclusion, although there are studies on the care burden of individuals providing care for cancer patients in the

world and in Turkey (3,12,13-16), there were limited number of studies towards life quality (6,8,17,18) at the time of the study. Therefore, this study was carried out to determine care burden, quality of life of caregiving family members and the affecting factors.

Materials and Methods

Research design and sampling

It is a descriptive study. The study was conducted between October 2016 - April 2017 with the individuals caring for cancer patients who were treated in the a hospital. The universe of the study consisted of 202 caregivers. The sampling method was not used in the study and it was aimed to reach the whole universe, but 160 caregivers who agreed to participate in the study composed the sample.

Data collection tools

Caregiver identification form: It was prepared by the researchers in order to determine the demographic and care related characteristics of participants. It consists of 18 questions.

The caregiver quality of life index-cancer (CQOLC) scale:

The Caregiver Quality of Life Index-Cancer was developed by Weitzner et al. (16) in 1999 and measures the quality of life of caregivers for cancer patients. Its Turkish validity and reliability study was conducted by Karabuğa and Pınar in 2013 (6). It is a 5 point Likert-type assessment and each item is scored from 0 to 4 (0 = none, 1 = low, 2 = a little, 3 = high, 4 = very high). The raw score for each sub-scale is multiplied by 35 to 14, divided by the number of expressions answered and the score of the sub-dimensions is determined. The score on the whole scale is calculated by summing the scores for the answers given to the 4 sub-dimensions and the answers given to the 8 expressions, in other words it is calculated by summing the scores of the answers given to all expressions in the scale multiplied by 35 and divided by the number of expressions. With this scoring method, the score of the each sub-scale and scale varies between 0 and 140. A higher score indicates a better quality of life (6,16). The Cronbach's alpha value of the scale is 0.88 (6). In this study, Cronbach's alpha value was found to be .90 for the quality of life scale.

Burden interview: It was developed by Zarit, Reever and Bach-Peterson in 1980 and identifies the difficulties experienced by caregivers (17). The Turkish validity and reliability study was conducted by İnci and Erdem in 2006 and consists of 22 statements determined the effect of caregiving on caregivers lives (physical, mental and social well-being) (18). It is a 5-point Likert-type scale, each item is scored from 0 to 4, "never", "rarely", "sometimes", "often", "always". A minimum score can be obtained from the scale is 0 while maximum score is 88. The score intervals are determined as 0 – 20 points: no care burden, 21–40 points: low care burden, 41 - 60 points: moderate care burden, and 61-88 points: high care burden.

The items in the scale are generally for social and emotional fields, and a higher score indicates that the problems experienced are bigger. The Cronbach's alpha value of the scale is 0.83 (18). In our study, the Cronbach's alpha value of the burden interview was found to be 0.88.

Variables of the study

The dependent variables are the mean scores on the caregiver quality of life index-cancer scale and the scores on the burden interview. The independent variables are socio demographic characteristics and care-related characteristics.

Collecting data

The data were collected by face to face method. The data collection process was carried out in chemotherapy and oncology clinics. A quiet environment was created for the interview. The interview took an average of 20-25 minutes.

Ethical Approval

The required ethics committee approval was obtained from the ethics Committee of Harran University (Date: 07 September 2016, No: 74059997.050.01.04-161), the permission was obtained from the institution where the study was conducted, and the informed consents were obtained from the individuals providing care for the cancer patient who agreed to participate in the study.

Statistical analysis

Statistical package for social sciences (SPSS) 16.0 package program was used to evaluate the data. Descriptive statistics (number, percentage, mean), Independents Samples t Test, Kruskal-Wallis Test, Mann Whitney U test were used for data analysis.

Results

The mean age of the caregiving individuals was 34.78 ± 1.25 years and 52.5% of them were male, 66.9% of them were married, 20.0% of them were university graduates, 47.5% of them had incomes lower than their expenses and 60.0% of them were not employed (Table 1).

According to their their statements, 60.0% of the caregivers had difficulties in working life; 21.8% of them had previously provided care for another patient; 89.4% of them gave care because of family commitments/family bonds. The mean duration of caregiving was 2.35 ± 2.16 (1-12) years and 58.1% of them stated that there was another individual helping them during care. 98.1% of the caregivers were family members; 61.2% of them were affected negatively in terms of health; 43.1% of them had a deterioration in their mental health status; 95.6% of them fulfilled their responsibilities; 40.0% of them had difficulties in working life. It was found that 92.5% of them did not receive training about caregiving and 75.0% of those received training from health workers.

The mean score of the caregivers on the whole Burden Interview was 32.65 ± 15.14 and their mean score on the whole CQOLC was 78.75 ± 16.31 (Table 2).

Table 1. Demographic characteristics of caregivers (n = 160)

Variables	n	%
Age		
Under 45 years	126	78.8
45 years old	34	21.3
Gender		
Woman	76	47.5
Male	84	52.5
Marital status		
Themarried	107	66.9
Single	53	33.1
Education status		
Illiterate	24	15.0
Literate	6	3.8
Primary school	30	18.8
Middle school	22	13.8
High school	46	28.8
Üniversity	32	20.0
Income status		
Income less than expense	76	47.5
Income expense equal	69	43.1
Income more than expense drum	15	9.4
Employment Status		
Employe	63	39.4
Unemploye	97	60.6
Total	160	100.00

Table 2. Burden interview and caregiver quality of life index-cancer scale score averages

Scales	$\bar{X} \pm SD$	Min-Max Points
Burden Interview		
Total score	32.65 ± 15.14	5.00-83.00
Caregiver Quality of Life Index-CancerScale		
Load	68.77 ± 28.12	10.50-140.00
Discomfort	93.96 ± 29.12	0.00-140.00
Positive adaptation	83.59 ± 29.48	0.00-140.00
Financial troubles	74.22 ± 40.61	0.00-140.00
Total Score	78.75 ± 16.31	42.00-122.00

There was no significant difference between the mean scores of the caregiving individuals on the whole Burden Interview ($t = -.928$, $p = .355$) and the whole CQOLC ($t = .717$, $p = .475$) according to gender. While there was no statistically significant difference between the mean scores of the whole Burden Interview according to education level ($K-W = 2.426$, $p = .788$), a statistically significant difference was found between the mean scores on the financial difficulty subscale of the CQOLC ($K-W = 15.290$, $p = .009$). There was no significant difference between the mean scores on the whole Burden Interview while there was a significant difference between the mean scores on the whole CQOLC scale according to income status ($K-W = 4.180$, $p = .124$), ($K-W = 7.632$, $p = .022$) (Table 3).

Discussion

Cancer is an important public health problem. This problem can be solved by a multi-step and very complex process (19).

Table 3. Comparison of the mean scores on the burden interview and the caregiver quality of life index-cancer scale according to some characteristics of caregivers.

Variables	Scales					
	Burden Interview $\bar{X}\pm SD$	Caregiver Quality of Life Index-Cancer Scale				
		Burden $\bar{X}\pm SD$	Disruptiveness $\bar{X}\pm SD$	Positive adaptation $\bar{X}\pm SD$	Financial concern $\bar{X}\pm SD$	Total $\bar{X}\pm SD$
Age						
Under 45	33.10±15.21	66.77±28.25	92.73±29.83	86.19±27.93	72.59±40.76	77.93±16.67
45 years old	31.00±14.98	79.88±30.02	98.52±26.27	73.97±33.36	80.29±40.08	81.76±14.73
Statistical value	t= -.717 p=.474	t= -2.549 p=.012	t= -1.029 p=.305	t= 2.169 p=.032	t= -.981 p=.328	t= -1.216 p=.226
Gender						
Woman	31.48 ± 14.66	66.80 ± 31.80	96.77 ± 29.91	16.69 ± 6.08	79.67 ± 40.65	17.18 ± 5.29
Male	33.71 ± 15.58	68.75 ± 26.66	91.42 ± 28.33	16.73±5.76	69.30 ± 40.18	17.26 ± 17.26
Statistical value	t= -.928 p=.355	t= .011 p=.991	t= 1.161 p=.247	t= .453 p=.965	t= 1.620 p=.107	t= .717 p=.475
Marital status						
Themarried	32.76 ± 15.45	20.42 ± 8.28	18.77 ± 5.83	15.94 ± 6.04	6.53 ± 3.52	17.40 ± 4.51
Single	32.43 ± 14.63	18,07 ±8.24	18.83 ± 5.85	18.28 ± 5.30	6.01 ± 3.39	16.86 ± 5.66
Statistical value	t= -.130 p=.897	t= 1.694 p=.092	t= -.056 p=.956	t= -2.396 p=.018	t= .878 p=.381	t= .367 p=.714
Education status						
Illiterate	35.25 ± 15.91	72.91 ± 33.13	93.33 ± 25.56	81.66 ± 35.83	5.29 ± 4.02	15.75 ± 4.31
Read and writed	33.83 ± 15.96	71.75 ± 26.72	91.66 ± 21.36	71.66 ± 2 7.14	7.66 ± 3.88	18.33 ± 4.36
Primary school	31.66 ± 16.22	75.13 ± 31.73	98.00 ± 30.92	74.83 ± 35.97	7.46 ± 3.43	17.80 ± 5.41
Middle school	35.00 ± 18.57	65.54 ± 28.64	95.45 ± 30.11	86.59 ± 28.92	6.27 ± 2.93	17.90 ± 4.55
High school	31.04 ± 11.90	65.43 ± 26.16	94.23 ± 29.90	91.84 ± 20.58	5.23 ± 3.22	18.06 ± 4.83
University	32.12 ± 15.73	66.17 ± 29.07	89.68 ± 30.79	81.56 ± 27.92	7.56 ± 3.16	15.90 ± 5.11
Statistical value	K-W=2.426 p=.788	K-W=2.235 p=.816	K-W=1.696 p=.889	K-W=6.726 p=.242	K-W=15.290 p=.009	K-W=2.693 p=.747
Income status						
Income less than expense	35.13 ± 13.97	18.48 ± 7.75	17.94 ± 5.32	17.21 ± 5.87	5.19 ± 3.55	16.15 ± 4.73
Income expense equal	30.52 ± 15.98	21.05 ± 8.80	19.46 ± 6.23	16.00 ± 5.90	7.59 ± 3.04	18.36 ± 4.70
Income more than expense drum	29.93 ± 15.98	19.06 ± 8.37	20.00 ± 6.08	17.53 ± 6.03	6.60 ± 3.18	17.40 ± 5.82
Statistical value	K-W=4,180 p=.124	K-W=2.845 p=.241	K-W=4.514 p=.105	K-W=1.555 p=.460	K-W=16.502 p=.000	K-W=7.632 p=.022
Employment status						
Employe	32.30 ± 14.68	21.01 ± 7.40	18.42 ± 5.97	15.98 ± 5.56	6.68 ± 3.23	18.30 ± 4.41
Unemploye	32.88 ± 15.51	18.76 ± 8.97	19.03 ± 5.74	17.19 ± 6.08	6.15 ± 3.63	16.52 ± 5.11
Statistical value	t= -.238 p=.812	t= 1.683 p=.094	t= -.638 p=.525	t= -1.272 p=.205	t= .937 p=.350	t= 1.039 p=.300
Maintenance time						
1 year - 2 year	31.73 ± 16,04	19.65 ± 8.58	19.04 ± 6.12	16.83 ± 6.00	6.45 ± 3.56	16.95 ± 4.89
3 year - 4 year	32.66 ± 12,27	19.25 ± 7.26	18.50 ± 5.11	18.00 ± 5.35	6.12 ± 3.63	17.50 ± 5.25
5 years and up	37.40 ± 12.56	20.04 ± 8.32	17.81 ± 4.98	14.72 ± 5.64	6.13 ± 2.96	18.31 ± 4.65
Statistical value	K-W=3.638 p=.162	K-W=0.414 p=.813	K-W=2.278 p=.320	K-W=3.661 p=.160	K-W=0.407 p=.816	K-W=1.288 p=.525
Negatively affected health						
Yes	35.02 ± 15.07	66.11 ± 27.37	89.20 ± 29.59	81.50 ± 27.62	71.28 ± 39.69	16.73 ± 4.85
No	28.71 ± 14.55	73.20 ± 31.57	1.01 ± 26.72	87.08 ± 32.30	79.13 ± 41.98	18.05 ± 4.93
Statistical value	t=2.594 p=.010	t=-1.497 p=.136	t=-2.727 p=.007	t=-1.161 p=.247	t=-1.186 p=.237	t=-1.654 p=.100

In this study, it was found that the caregivers had a low caregiving burden. In a similar way, the studies reported that the caregivers had a low caregiving burden (7, 20). Contrarily, there are also studies which determined that the caregiving burden of the caregivers was high (21,22). Low caregiving burden of the caregivers in our study can be explained by the fact that more than half of the caregivers received support from other individuals during caregiving. In the study, the caregiving burden of the caregivers aged 45 years and younger was higher while no significant relationship was found between age and quality of life. Lim et al. (23) reported that age did not have an effect on quality of life. In the literature, it was found that there was no significant difference between age groups in terms of caregiving burden (7,21,24,25). Cain and Wicks (26) and Takata et al. (27) found that the caregivers who were younger than 55 years experienced exhaustion more. Similar to this study, Tel et al. (28) found that the caregiving burden of the individuals under the age of 45 was high. In our study, we expected that the caregiving burden of caregivers under the age of 45 would be high.

No significant relationship was found between the educational status and caregiving burden of caregivers. Iconomou et al. (5) stated that caregiving burden increases as the level of education decreases. In contrast to this study, Orak ve Sezgin (7) found a significant relationship between education and caregiving burden. In the study, high caregiving burdens of the caregivers with low education level may be an indication that awareness about caregiving is not sufficient.

In this study, it was found that the income levels and employment status of the patients' relatives did not affect the caregiving burden. In other studies, it was similarly stated that care burden of caregivers is not affected by income (7,20,21). In the study of Şahin et al. (29) no significant relationship was found between the employment status and caregiving burden of the caregivers. The results of the study were found to be consistent with the literature. While no difference was found between the caregiving burden of the caregivers according to the duration of caregiving, it was determined that the caregiving burden increased with the prolongation of the duration of caregiving. In other studies, it was stated that the caregiving burden increases as the duration of caregiving is prolonged (7,28,30)

In the study, the caregiving burden of the caregivers aged 45 years and younger was low. A study reported that the age of the caregivers affected their quality of life (39). Similar to our study, Tel et al. (28) found that the quality of life of the individuals aged under 45 years was low. In this study, the low life quality of the caregivers under 45 years is an expected result and can be explained by the high caregiving burden of them.

to their statements. In other studies, it was found that caregiving burden negatively affected the health of caregivers such as mental depression, anxiety, and deterioration in physical health (5,6,31-36). In the literature, this situation was explained by physical wear of individuals who giving care for cancer patients, compromising in terms of personal life, diminishing social relations, adversely affected family interactions and financial difficulties (37). Therefore, the findings of our study are consistent with the literature.

Not only the caregiving burden of individuals providing care for cancer patients is affected but also their quality of life is also affected (32). In this study, more than half of the caregivers stated that they received support from other family members about caregiving, and almost all of them stated that they undertook caregiving because there was no one to take care of the patient. Atagün et al (38). reported that caregiving responsibility is generally undertaken by first-degree relatives of patients. In another study, it was reported that 71.7% of the caregivers shared the caregiving process with someone and the quality of life of the caregivers was higher when they shared the caregiving responsibility with other (32). We also determined that the quality of life of the caregivers was not at the desired level. Similarly, other researchers stated that the quality of life of the individuals providing care for patients decreased (16). This finding can be explained by the fact that the health of more than half of the caregivers stated that their health was negatively affected while almost all caregivers defined caregiving as a family responsibility. In our study, it was found that age did not affect the quality of life of the caregivers and the quality of life of the caregivers aged 45 years and younger was low. A study reported that the age of the caregivers affected their quality of life (39). Similar to our study, Tel et al. (28) found that the quality of life of the individuals aged under 45 years was low. In this study, the low life quality of the caregivers under 45 years is an expected result and can be explained by the high caregiving burden of them.

In the study, it was determined that the gender of the caregivers did not affect their quality of life. In contrast, other studies in the literature stated that gender affects life quality (39). Our findings may be as a result of the close numbers of male and female caregivers.

We found that the educational status of the caregivers did not affect the quality of life. Lim et al. (24) reported that educational status does not affect the quality of life. However, other study stated that the quality of life of caregivers is affected by their educational status (6) The results of this study may suggest that the caregivers had similar levels of awareness because they did not receive any professional support.

In this study, it was found that the duration of caregiving did not affect the quality of life; as the caregiving time was prolonged, the quality of life improved. In the literature, the quality of life of caregivers is adversely affected due to

longer duration of care period and this effect is also negatively reflected in the care given to the patient (9,28). The increase in the quality of life as a result of the prolonged duration of caregiving suggests that they accepted the current situation and adapt their lives for this situation. In addition, the existence of individuals providing support to caregivers may have had a positive impact on their quality of life.

Conclusions

In the study, it was found that the caregivers had a low level of care burden and their life quality was not at the desired level. In the study, it was found that the caregivers had a low level of care burden and their life quality was not at the desired level. It was also found that the care burden of caregiving individuals was affected by their negative perceptions about their health while income status affected life quality.

In line with these results, it can be recommended to disseminate education programs which are conducted by health professionals to raise awareness for increasing the quality of life and reducing the burden of care, and to conduct nursing studies to determine the general health status of caregivers.

Ethical Approval: The required ethics committee approval was obtained from the ethics Committee of Harran University (Date: 07 September 2016, No: 74059997.050.01.04-161), the permission was obtained from the institution where the study was conducted, and the informed consents were obtained from the individuals providing care for the cancer patient who agreed to participate in the study.

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Concept: S.C.G., F.E.

Literature Review: S.C.G., F.E.

Design : S.C.G., F.E.

Data acquisition: S.C.G., F.E.

Analysis and interpretation: S.C.G., F.E.

Writing manuscript: S.C.G., F.E.

Critical revision of manuscript: S.C.G., F.E.

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