

RESEARCH ARTICLE

Effects of Care Burdens of Caregivers of Cancer Patients on their Quality of Life

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Abstract

In this study, the aim was to examine the effects of caring burdens of family caregivers of cancer patients on their quality of life in the east of Turkey. Data were collected at the Chemotherapy unit of Yakutiye Research Hospital of Ataturk University. Participants were 18 years old and older. The sample included 190 family caregivers who were living in the same flats with the patients during caregiving. Data were collected using a questionnaire that included socio-demographic questions for family caregivers and the Burden Interview, and the Caregiver Quality of Life Index-Cancer (CQOLC) Scale. SPSS version 14.0 was used to analyse the data. Descriptive statistics were computed for demographic variables of family caregivers. Pearson correlation analysis was used to analyze the relationship between the care burden and quality of life, linear logistic regression analysis was applied to determine the effect care burdens have on the quality of life, and logistic regression analysis was employed to determine the effect descriptive characteristics and care-related properties have on the quality of life. The score mean of the burden interview of caregivers was 36.6 ± 11.2 ; and their score mean of CQOLC was 81.4 ± 17.3 . This study concluded that there was a negative relationship between caring burdens and the quality of life ($p < 0.001$); descriptive characteristics, caring-related properties, and caring burden variables were all significant predictors of the quality of life. It is recommended that caregivers are given support by being offered training about providing care.

Keywords: Cancer - caregiver - caring burdens - quality of life - Turkey.

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Introduction

Cancer is the second highest cause of death among adults and the mortality rate from cancer had increased to nearly 130 per 100,000 populations in 2000 and 2003 in Turkey. Based on the latest report of the Turkish Statistical Institute, 23.681 were dead in 2000 and 23.775 were dead in 2003 because of cancer (Turkish Statistical Institute, 2006). These numbers imply that more and more families in Turkey have to live with and care for a relative suffering from cancer. Family caregivers play a central role in managing all aspects of the patient's care (Northouse, 2005). Family structure has an extremely important place in traditional Turkish culture, and caregivers are affected by this structure. In addition, the homecare system in our country is not as well-established as it is in developed countries. As a result, informal care is more widespread than formal care. In general, the responsibility of caring for the cancer patient at home is down to the patient's spouse, children, relatives, or friends (Kuşçu et al., 2009). Family caregivers who care for cancer patients may have to cope with a variety of physical, social, and economic problems during the caregiving process. The decrease in the caregiver's quality of life influences the

quality of care and thus the QOL of the patient. Research on family caregivers has consistently demonstrated that increased caregiver burden is related to reduced mental and physical health (Morimoto and Schreiner, 2003). The family life/marital life, career, health state, and social life of caregivers of cancer patients are also adversely affected during this process (Babaoğlu and Öz, 2003; Borneman et al., 2003; Grunfeld et al., 2004; Carter, 2005; Dumont et al., 2006; Chang et al., 2007; Chen et al., 2007).

Caregiving can significantly influence the QoL of these caregivers because of the fear of losing their loved one, the substantial impact of caring on the financial well-being of caregivers, and restrictions regarding their social life (Hagedoorn et al., 2000; Edwards and Ung, 2002; Chen et al., 2004). Having good relationships with patients, good friendships, their marital status, and the social support which they receive from family members are factors that contribute the caregiver's quality of life positively (Francis et al., 2009). There is a positive relationship between the physical health status, social relationship status, and environmental influences of caregivers and their quality of life (Hughes et al., 1999). Studies also state that caregivers experience physical, social, psychological, and economical issues during the time they provide care to the

patient; ultimately, causing an increase in care burdens and a deterioration in their quality of life (Morimoto, 2003). Studies report that characteristics such as age, gender, education level, income status, care period, changes in social life, and lack of family support have an effect on the quality of life of caregivers providing cancer patients with care (Tang et al., 2008; Özer et al., 2009; O'Hara et al., 2010; Alptekin et al., 2010; Kim, 2010; Tamayo et al., 2010; Collins, 2011; Hacialioglu et al., 2011; Kim et al., 2011; Song et al., 2011).

As the number of the studies conducted in Turkey is very low, the data about the burden and quality of life scores of cancer patients' caregivers is very scarce. Therefore, we conducted this study to evaluate the QoL of caregivers of cancer patients in different populations. It is thought that the planned care will decrease burdens of caregivers and help increase their quality of life.

Materials and Methods

The aim of this study was to evaluate the effect burdens of family caregivers for cancer patients on their QoL, in the east Turkey. This study utilized a descriptive design. The participants were 290 family caregivers who came together with cancer patients to the Chemotherapy unit of a university hospital in Turkey between March and June 2010. The family caregivers were selected through convenience sampling and 210 of them were contacted but only 190 of them responded to the questionnaire.

Participants

To be included, caregivers had to be: aged 18 years or more, able to read and understand the Turkish language, able to come to the Chemotherapy unit together with the patients, giving care to patients for at least 3 months, living with the patients during caregiving, at least primary school graduates, willing to participate in this study. Permission to undertake this study was gained from the Head of the Medical Oncology Department and informed consent was obtained from each family caregiver. The family caregivers were informed about the purpose of the research and were assured of their right to refuse participation or to withdraw from the study at any stage.

Instruments

The data collection questionnaire had three sections: demographic data form, The Burden Interview and *The Caregiver Quality of Life Index-Cancer (CQOL-C)* Scale. The demographic data form included age, gender, employment status, marital status, education, relationship to patient, the number of children, duration of caregiving, support from other family members during caregiving, perception of health during and income.

Zarit Burden Interview (ZBI), a 22 item, 5-point Likert scale (never = 0, nearly always = 4) used widely to assess caregiver burden. The total burden was obtained by adding the scores for all items with a range of 0 to 88, higher scores indicating greater burden (Zarit, 1980).

The CQOLC was developed by Michael A. Weitzner the and the validity and reliability of the Turkish form was studied by Bektaş and Özer (2009), and Karabuğa (2009). The scale measured four conceptual domains of

QoL: physical functioning, emotional functioning, family functioning and social functioning. The CQOLC consists of 35 items that have a five-point Likert format that ranged from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 (very much): ten items relate to burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns and eight single items to additional factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about illness, protection of patient, management of patient's pain and family interest in caregiving) The CQOLC scale is scored by adding up the score on each item to yield a total score for the instrument and scores can range from 0-140. For all items and domains that measure QoL, a higher score represents a better QoL (Weitzner et al., 1997).

Design

The research visited the Chemotherapy unit five working days every week. Family caregivers who brought their patients to the polyclinic for examination were interviewed in the polyclinic and the ones who brought their patients to the Chemotherapy Unit for chemotherapy were interviewed in the Chemotherapy Unit. The Burden Interview and *The Caregiver Quality of Life Index-Cancer (CQOL-C)* Scale was explained to the participants, who then read it and marked their answers on the sheets. The questionnaire took approximately 15 min to complete and could be understood by family caregivers with minimal reading ability.

SPSS version 14.0 was used to analyse the data. Descriptive statistics were computed for demographic variables of family caregivers. Pearson Correlation Analysis was used to analyze the relationship between the care burden and quality of life, Linear Logistic Regression Analysis was used to determine the effect care burdens have on the quality of life, and Logistic Regression Analysis was used to determine the effect descriptive characteristics and care-related properties have on the quality of life.

Results

In this study, 40% of caregivers were under 35 (average age: 42.3±13.6), 58.9% were female, 78.9% were married, and 65.8% were primary school graduates (Table 1).

In this study, 38.4% of caregivers were the son or daughter of the patient, 32.1% had been caring to the patient for over a year, and 75.3% of patients had their own room (Table 2).

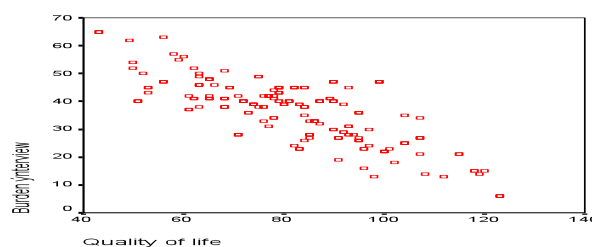


Figure 1. The Relationship Between the Care Burden and the Quality of Life.

Table 1. Descriptive Characteristics of Caregivers

Demographic variables	n	(%)	
Age (years)	<35	76	40.0
	36-50	64	33.7
	51-65	41	21.6
	66-80	9	4.7
Gender	Female	112	58.9
	Male	78	41.1
Education	Illiterate	17	9.0
	Primary	125	65.8
	Secondary	36	19.0
	University	12	6.2
Health insurance	Yes	150	78.9
	No	40	21.1
Income	Low	117	61.6
	Equal	73	38.4
Employment status	Employed	42	22.1
	Unemployed	148	77.9
Marital status	Married	150	78.9
	Single	34	17.9
	Divorced	6	3.2

Table 2. Care-Related Properties of Caregivers

Variables	n	(%)
Caregiver/patient family relationship		
Daughters/sons	73	38.4
Spouse	59	31.1
Parents	9	4.7
Sisters/brothers	12	6.3
Other	37	19.5
Duration of the care		
<2 month	52	27.4
3-6 month	26	13.7
6-9 month	32	16.8
9-12 month	19	10
Over a year	61	32.1
The patient has their own room		
Yes	143	75.3
No	47	24.7

For this study, the mean score of Burden Interview of caregivers was 36.65 ± 11.21 , and their mean score of Caregiver Quality of Life Index-Cancer was 81.40 ± 17.3 . The Caregiver Quality of Life Index sub-scale scores of caregivers were 21.18 ± 5.3 for "burden," 14.96 ± 4.8 for "disruptiveness," 12.31 ± 3.9 for "positive adaptation," and 5.69 ± 3.0 for "financial difficulties" (Table 3).

There was a negative relationship between the caring burden and quality of life; as the care burden increased, the quality of life score decreased; the difference was statistically significant ($p < 0.001$) (Figure 1).

For this study, Linear Regression Analysis was used to determine the effect care burdens of caregivers have on their quality of life (Table 4). The Table illustrates that the care burden variable explains 60% of the total variance of the quality of life. The t-test results regarding the significance of regression coefficients prove that care burden variable is a significant predictor on the quality of life ($p < 0.001$).

All variables used in this study were included in the logistic regression model to determine which factors have an effect on the quality of life of caregivers, and to what extent (Table 5). These variables were the characteristics

Table 3. The Burden Interview Score Mean and Caregiver Quality of Life Index-Cancer Score Mean of Caregivers

Variables	Total items	Range of scores	X±SS
Burden Interview	22	3-65	36.65 ± 11.2
Quality of Life			
Burden	10	4-35	21.18 ± 5.3
Disruptiveness	7	5-25	14.96 ± 4.8
Positive adaptation	7	4-21	12.31 ± 3.9
Financial difficulties	3	0-9	5.69 ± 3.0
Total CQOLC	35	43-123	81.40 ± 17.3

Table 4. An Analysis of the Effect Caring Burdens of Caregivers have on their Quality of Life using Regression Analysis

Variable	B	Standard error B	Standardized B	P	R ²
Burden Interview					
	-1,229	0.072	-0.782	0.000	0.611

Table 5. An Analysis of Factors Having an Effect on the Quality of Life of Caregivers using Logistic Regression Analysis

	B	SE	Wald	P	Exp(B)
Constant	-2,661	1,210	4,840	0.028	0.070
Variables					
<35 age	-4,797	1,409	11,590	0.001	0.008
36-50 age	-3,118	1,287	5,871	0.015	0.044
Low income	-3,322	0.680	23,825	0.000	27,722
Spouse	-2,519	0.754	11,158	0.001	0.081
Parents	-2,460	1,105	4,958	0.026	0.085
The patient does not have their own room	1,645	0.498	10,934	0.001	0.193

of caregivers and the characteristics of the care situation. Results of logistic regression analysis, conducted on a model incorporating all variables, concluded that factors that had an effect on the quality of life were being under 35, being between 36 and 50, having a low income, being the spouse and parent of the patient, and the patient having their own room ($p < 0.05$).

Discussion

Cancer is a chronic disease that causes patients and caregivers to lose control over their lives, has an adverse effect on their social, work, family/marital life, and causes their health and quality of life to deteriorate. Conducted studies report that the majority of caregivers experience health issues, domestic problems, and their quality of life decreases. Other studies addressed these problems under categories titled "disturbance", "burden" and "quality of life;" they concluded that the issues they experience were parallel to those experienced by the patient (Foxall and Gaston- Johansson, 1996; Nijboer et al., 1998; Weitzner et al., 1999a; Carter and Chang, 2000; Andrews, 2001; Babaoğlu and Öz, 2003; Borneman et al., 2003; Grunfeld et al., 2004; Carter, 2005; Gaugler et al., 2005; Grov et al., 2005; Dumont et al., 2006; Bostancı et al., 2007; Chang et al., 2007; Chen et al., 2007; Mystakidou et al., 2007).

The mean score of the Burden Interview of caregivers was 36.65 (Table 3). Studies have found that care burden

of the average 18.5-29.16 (Grunfeld et al., 2004; İnci, 2006; Higginson and Gao, 2008; Higginson et al., 2009; Yusuf et al., 2010). The reported mean Burden Interview score of caregivers for this study was higher in comparison to those stated in literature. In Turkish society, family caregivers play a main role in the treatment of cancer patients because of the Turkish cultural plural of expectation and obligations.

In this study, the total score of Caregiver Quality of Life Index was 81.4. In comparison to literature, the total score of Caregiver Quality of Life Index of this study is above average. The total score of Caregiver Quality of Life Index for other studies was 80.1 (Tang, 2009), and 71.77 (Bektaş and Özer, 2009). Our data are compatible with these findings.

In this study, there was a negative relationship between the care burden of caregivers and their quality of life (Figure 1). In their studies, Gaston- Johanson et al. (2004) and Rhee et al. (2005) stated that there was a relationship between burden experienced by caregivers and their quality of life. Yun et al. (2005) reported that burden of caregivers had an adverse effect on their quality of life. Another study reported that variables such as bad health conditions, lack of family support, and financial difficulties increased the burden of caregivers and decreased their quality of life scores (Dumont et al., 2006). For caregivers, their sense of burden, tendency of depression and anxiety, and sleeping disorders increase, and their quality of life decreases when the patient's burden/strain increases and their symptoms become uncontrollable (Nijboer et al., 1998, Weitzner et al., 1999a, Grunfeld et al 2004, Carter, 2005, Grov et al., 2005, Babaoğlu and Öz, 2007). This study also identified a relationship between care burdens and the quality of life, just as stated in literature (Tang et al., 2008; Özer et al., 2009; Alptekin et al., 2010; O'Hara et al., 2010; Kim, 2010; Tamayo et al., 2010; Collins, 2011; Song et al., 2011).

When determining the effect care burdens of caregivers have on their quality of life, this study proved that the care burden variable explains 60% of the total variance in the quality of life, and that care burden variable is a significant predictor on the quality of life (Table 5). In their study, Yun et al. (2005) reported that the burden experienced by caregivers explained 41% of the total variance in the quality of life. This result supports our study.

Logistic regression analysis concluded that descriptive characteristics of caregivers and characteristics of the care situation affect their quality of life (Table 6). Gender, age, income status, their relationship with the patient, whether or not the patient had their own room, and the perception level of the patient regarding their health were the most important factors that had an effect on the quality of life of caregivers. In their study, Meyers and Gray (2001) identified that socio-demographic characteristics of caregivers explained 44% of the total variance in the quality of life, and that these characteristics were a significant predictor for the quality of life. This situation is expected when we take into consideration that descriptive characteristics and experienced issues are the most important factors that have an effect on lives of caregivers.

In conclusion, the effects of providing care for patients with cancer on caregiver quality of life have not yet been acceptably explored in Turkey. In this study, demographics of caregivers and the care burden had an effect on the quality of life of caregivers. Variables that have a predictor effect on the quality of life can be set forth clearly in the event that the sampling group is broadened in these types of studies.

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