

Research Article

Quality of Life of Caregivers of Women Receiving Cancer Treatment in Turkey

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Abstract

AIM: The study aims to explore the predictors of the quality of life of caregivers of women receiving cancer treatment in Turkey.

METHOD: This study was conducted in a Medical-Oncology inpatient clinic of a University Hospital in Istanbul, Turkey, between February and June 2020. Descriptive data were collected from 128 family caregivers using caregiver and patient identification forms and the quality of life scale—family version. Bivariate analyses and multiple regression were used to analyze the data.

RESULTS: The mean score of the quality of life was 4.41 (standard deviation=0.63). A backward multiple regression revealed that being female caregivers, increased time spent for care per day, and caring for women with metastatic cancer were factors associated with poor quality of life.

CONCLUSION: Although caregiving responsibilities bring challenges to every caregiver, those who are at high risk for impaired quality of life during caregiving need further support in their caregiving to maintain quality of life. Further research should focus on finding solutions to better support caregivers who are experiencing impairment in their quality of life.

Keywords: Caregiver, female cancer patients, quality of life

Introduction

Cancer is a chronic condition with a growing number of informal caregivers providing care for patients with cancer (Treanor et al., 2019). Informal caregivers who are not health professionals provide care for a partner, family member, or a friend affected by cancer (American Cancer Society, 2021; Treanor et al., 2019). The informal caregiving role mainly falls on a family member who provides care at no cost (American Cancer Society, 2021). Patients with cancer primarily rely on their caregivers for emotional, financial, and physical support, including navigating complex healthcare systems, medical appointment planning, managing side effects of the treatment, and helping with activities of daily living (Areia et al., 2019; Schulz & Eden, 2016). Yet, the needs of patients with cancer may vary based on the cancer type, stage, treatment, and presence of comorbidities (Areia et al., 2019). Family caregivers play a crucial role in supporting patients; however, they face numerous physical and psychosocial challenges (Cai et al., 2021; Lim et al., 2017; Lee et al., 2021), highly impairing their quality of life (QoL).

While caregiving might be a meaningful experience especially for the family members, it is also associated with poor QoL, increased psychosocial problems, and even increased risk of mortality in the caregivers (Areia et al., 2019; Geng et al., 2018;

Govina et al., 2019; Lim et al., 2017). The psychosocial effect of cancer diagnosis and treatment-related stress negatively affect family caregivers while balancing their lives and caregiving roles. Recent evidence on family caregivers shows that cancer caregivers, especially key family members (usually partners), are at risk for psychological distress with a prevalence of 25–30% (Caruso et al., 2017). The caregiving roles that ultimately affect the QoL (Lim et al., 2017) include providing emotional support, helping with activities of daily living, and dealing with other aspects of care (Caruso et al., 2017).

Female cancer patients may have a higher symptom burden than male patients (Bubis et al., 2018), and they may be at risk for higher levels of stress related to cancer diagnosis and its social complications (e.g., divorce, social isolation, and stigmatization) (Okediji et al., 2017). In addition, these patients may have multiple responsibilities such as caring for children and household management (Treanor et al., 2019) and tend to have more unmet needs, especially in the psychological aspect of QoL (Puts et al., 2012; Rahmani et al., 2014). Hence, these findings indicate the need to focus on caregivers of women with cancer to understand who is caring for women undergoing cancer treatment and how this role affects caregivers' QoL. While this is of particular concern for some countries such as Turkey given the high cultural expectation of women's role in the family, there is

limited literature specifically addressing the QoL of caregivers of female patients with cancer (Hacialioglu et al, 2010). Therefore, this study aimed to examine the predictors of the QoL of family caregivers of women receiving cancer treatment in Turkey. In addition, factors predicting the subdimensions of QoL (i.e., psychological and spiritual health status, physical health status, approach to diagnosis status, and support and economic impact) were explored.

Research Questions

1. What are the quality of life levels of caregivers of women receiving cancer treatment according to the the quality of life scale-family version?
2. Do some sociodemographic characteristics of caregivers of women receiving cancer treatment affect the caregivers' quality of life scale family version score statistically?
3. Do some disease-related characteristics of women receiving cancer treatment affect their caregivers' quality of life scale-family version score statistically?

Method

Study Design

This study is descriptive.

Sample

This study was conducted in a Medical-Oncology inpatient clinic of a University Hospital in İstanbul, Turkey, between February and June 2020. A convenience sampling technique was used to recruit caregivers of women receiving cancer treatment. Caregivers older than 18 years, literate in Turkish, and having a kinship with the patients were eligible to participate in the study. All caregivers shared responsibility with the primary caregiver or family members who provided care in the hospital setting. These caregivers provided care for free. A total of 150 caregivers meeting eligible criteria were invited to the study during the data collection period. Twenty-two caregivers declined to participate in the study or did not complete the survey (85.3% response rate). Therefore, 128 caregivers of women who received cancer treatment were included in the study.

Data Collection Tools

The patient information form

The patient information form included six questions regarding women's cancer disease-related characteristics: age, primer cancer diagnosis, metastasis, time duration since diagnosis, the reason for the last hospitalization, and the ability to maintain self-care. Perceived ability to maintain self-care of patients was measured using the following question asked to the caregivers: "Is your patient able to provide care for herself?" (yes, no, or partially).

The caregiver's information form

The caregiver's information form included seven questions related to caregivers' sociodemographic and their caregiving roles: gender, age, employment status, living with the patient in the same house, having a chronic disease, having a separate room for caregivers at home, and average time of care per day.

Quality of life scale-family version

The quality of life scale—family version (QoL-FV) was developed by Ferrell and Grant (2005) to evaluate the QoL of patients with cancer and adapted to measure the QoL of family members. The scale consists of 37 items rated on a Likert-type scale ranging from the worst outcome (0) to the best outcome (10). The total score is calculated as the sum of all items divided by the number of items, with higher total scores indicating greater QoL (Ferrell & Grant, 2005). The current study used the Turkish version of the QoL-FV, which is composed of 31 items and four subdimensions: psychological and spiritual well-being (11 items); physical health (9 items); approach to diagnosis (7 items); and support and economic effect (4 items) (Okcin & Karadakovan, 2012). The approach to diagnosis (i.e., fear of recurrence, reactions, and feeling to diagnoses such as depression, sadness, and anxiety) is a new subdimension of the Turkish version of the QoL-FV. In addition, this version of the scale combines two subdimensions (i.e., psychological well-being and spiritual well-being) into one subdimension: psychological and spiritual well-being (i.e., coping, satisfaction with life, feeling hopeful, and having a life purpose). The Turkish version of the QoL-FV demonstrated validity, excellent internal consistency (Cronbach's alpha was .90), and test-retest reliability ($r=0.86$). In this study, the Cronbach's alpha value of the QoL-FV was .84.

Data Collection Procedure

The caregivers of women receiving cancer treatment at the inpatient oncology clinic were invited to participate in the study from February to June 2020. All caregivers were informed about the study purpose, methods, and approaches. Written informed consent was obtained from eligible participants. The caregivers filled the surveys independently in a private place in the hospital inpatient clinic. The primary researcher of this study was available for any questions or concerns that the participants might have about the study.

Statistical Analysis

Data were analyzed using Statistical Package for the Social Sciences 24.0 (IBM SPSS Corp., Armonk, NY, USA). Descriptive statistics were used, including frequencies and percentages for categorical variables and means and standard deviation (SD) for the continuous variables. The normality of the data was examined using the Kolmogorov-Smirnov normality test. Bivariate analyses (i.e., independent *t*-test, Mann-Whitney *U* test, Kruskal-Wallis analysis of variance, and one-way analysis of variance) were used to examine differences in the score of QoL-FV by patients' and caregivers' characteristics to build a regression model. Variables with *p*-values of less than .25 in the bivariate analyses were entered into the multiple regression models. Five multiple linear regression models with backward elimination were run to examine factors predicting the total score of the QoL-FV and each subdimension. *p*-Values of less than .05 were considered statistically significant for bivariate and multiple regression analyses.

Ethical Considerations

Ethical approval was obtained from for this study from the Koc University Ethical Committee Turkey (Date: February 7, 2020, NO: 2020.054.IRB3.026). In addition, written permission from the Koç University Hospital Nursing Services Directorate was obtained before conducting the study.

Table 1.
Demographics and Other Characteristics of the Caregivers (n = 128)

Characteristics	n	%
Gender		
Female	77	60.2
Male	51	39.8
Age group		
18–30	13	10.2
31–40	35	27.3
41–50	38	29.7
50 and above	42	32.8
Employment		
Yes	75	58.6
No	53	41.4
Living with the patient in the same house		
Yes	76	59.4
No	52	40.6
Chronic disease		
Yes	55	43.0
No	73	57.0
Having a separate room for themselves		
Yes	105	80.5
No	23	19.5
Average time of care per day		
1–6 hours	36	28.1
7–12 hours	44	34.4
13–18 hours	16	12.5
19–24 hours	32	25.0
Degree of kinship		
Mother	8	6.3
Sibling	26	20.3
Spouse	41	32.0
Others*	53	41.4

Note: *Others included family members such as children and cousins.

Results

Of the 128 caregivers, 60.2% were female and 32.8% were 50 years old and above. The majority of the caregivers were employed (58.6%) and lived with their patients in the same home (59.4%). The characteristics of the caregivers are shown in Table 1.

Of the women with cancer cared for by a family member, 64.1% were 50 years old and above and 33.6% had breast or gynecological cancer. Of these women with cancer, 38.3% were diagnosed in the last 0–6 months, and 65.6% had metastatic cancer. Less than half of women with cancer (42.2%) were reported to have the ability to maintain self-care for themselves by their caregivers (Table 2).

Table 2.
Disease-Related Characteristics of Patients with Cancer (N = 128)

Characteristics	n	%
Age group		
18–30	5	3.9
31–40	15	11.7
41–50	26	20.3
50 and above	82	64.1
Primer cancer diagnosis		
Breast–gynecological cancer	43	33.6
Lung cancer	19	14.8
Colorectal cancer	17	13.3
Pancreas cancer	14	10.9
Esophageal–stomach cancer	10	7.9
Brain tumors	6	4.7
Other cancer types (sarcoma, lymphoma, head–neck, leukemia, and kidney tumor)	19	13.8
Diagnosis time		
0–6 months	49	38.3
6–12 months	45	35.2
12–24 months	23	18.0
24+ months	11	8.6
Metastasis		
Yes	84	65.6
No	44	34.4
Ability to maintain self-care		
Yes	54	42.2
No	29	22.7
Partially	45	35.2
Reason for the last hospitalization		
Chemotherapy/radiotherapy	55	43.0
Symptomatic treatment	73	57.0

Table 3.
Descriptive Statistics of Quality of Life Scale—Family Version (QOL-FV)

	Mean (SD)	Minimum–Maximum
QOL-FV total	4.41 (0.63)	2.77–6.03
QOL-FV subdimensions		
Psychological and spiritual health status	5.44 (0.90)	2.82–7.09
Physical health status	4.88 (0.94)	2.33–7.78
Approach to diagnosis status	1.90 (0.83)	0.00–5.0
Support and economic impact status	4.92 (0.95)	1.25–7.0

Note: SD = standard deviation.

Table 4.
Examination of the Independent Variables Affecting the Total Quality of Life Score and Subdimension Scores by Regression Analysis

	B	SE	Beta	p	95% CI (Lower/Upper)
Total quality of life					
Caregiver's gender	.372	.078	.334	.000	.217/0.527
Average time of care per day	-.199	.035	-.415	.000	-.269/-0.130
Metastasis	.307	.083	.268	.000	.141/0.472
R^2			.397		
Adjusted R^2			.383		
F			27.224		
p			<.001		
Physical health status					
Caregiver's gender	.582	.137	.314	.001	.310/0.854
Average time of care per day	-.322	.062	-.403	.001	-.44/-0.199
Metastasis	.389	.147	.204	.009	.099/680
R^2			.328		
Adjusted R^2			.312		
F			20.168		
p			<.001		
Psychological and spiritual health status					
Caregiver's gender	.443	.139	.240	.002	.169/-0.132
Average time of care per day	-.258	.063	-.323	.001	-.383/-1.132
Employment	-.302	.141	-.164	.035	-5.581/-0.022
Metastasis	.472	.143	.247	.001	.188/0.756
R^2			.352		
Adjusted R^2			.331		
F			16.681		
p			<.001		
Approach to diagnosis status					
Caregiver's gender	.485	.141	.286	.001	.205/0.765
Metastasis	.377	.146	.216	.011	.089/0.666
R^2			.134		
Adjusted R^2			.121		
F			9.703		
p			<.001		
Support and economic impact status					
Average time to care per day	-.353	.067	-.422	.000	-.486/-0.219
Employment	.846	.155	.449	.000	.557/1/170
R^2			.246		
Adjusted R^2			.253		
F			22.456		
p			<.001		

Note: R^2 indicates the proportion of the variance in the dependent variable that can be explained by the independent variables. F -value represents the ratio of the explained variance of the regression model to the unexplained variance; it indicates if all independent variables are jointly significant.

SE = standard error.

The mean score of the QoL of the caregivers was 4.41 ± 0.63 , with scores ranging from 2.77 to 6.03. The mean scores and ranges of the QoL-FV subdimensions are presented in Table 3.

Table 4 shows the regression model results with the independent variables that were selected based on the bivariate analyses ($p < 0.25$) for the total and subdimension scores of the QoL. The model for the total QoL initially included nine variables based on the bivariate analysis: gender ($p < 0.001$), employment ($p = 0.05$), kinship type ($p = 0.027$), caregivers with their own room ($p = 0.05$), having someone in the family to give care ($p = 0.039$), the average time of care per day ($p < 0.001$), patient's ability to maintain self-care ($p < 0.001$), caring for patients with metastasis ($p < 0.001$), and the reason for the last hospitalization of patients ($p < 0.01$). Using the backward elimination method, the final regression model included three variables: the gender of the caregiver, the average time of care per day, and the metastasis status of the patient, which explained 38% of the variance (adjusted $R^2 = 0.38$, $F = 27.22$, $p < 0.001$). Being female caregivers ($\beta = 0.334$, $p < 0.001$), increased time spent for caregiving per day ($\beta = -.415$, $p < 0.001$), and providing care for patients with metastatic cancer ($\beta = 0.268$, $p < 0.001$) were significant predictors of the QoL (Table 4).

The model for the physical health status subdimension initially included six variables that were selected based on the bivariate analysis: gender ($p < 0.001$), the average time of care per day ($p < 0.001$), duration of the caregiving role ($p = 0.014$), patient's ability to maintain self-care ($p < 0.001$), caring for patients with metastasis ($p < 0.001$), and the reason for the last hospitalization ($p = 0.003$). The final regression model as shown in Table 4 included three variables (i.e., caregiver's gender, the average time of care per day, and cancer metastasis), which explained 31% variance in the QoL score (adjusted $R^2 = 0.31$, $F = 20.168$, $p < 0.001$).

The model for the psychological and spiritual health status subdimension initially included six variables that were selected based on the bivariate analysis: gender ($p < 0.001$), the average time of care per day ($p < 0.001$), duration of the caregiving role ($p = 0.04$), patient's ability to maintain self-care ($p < 0.001$), metastasis ($p < 0.001$), and the reason for the last hospitalization ($p < 0.001$). Table 4 shows the final regression model which included four variables (i.e., the caregiver's gender, the average time spent for caregiving per day, employment status, and cancer metastasis), which explained 33% of the variance in the QoL score (adjusted $R^2 = 0.33$, $F = 16.681$, $p < 0.001$).

The model for the approach to diagnosis status subdimension initially included four variables that were selected based on the bivariate analysis: gender ($p < 0.01$), employment status ($p = 0.237$), kinship type ($p < 0.001$), and cancer stage ($p < 0.01$). The final regression model revealed that two variables (i.e., caregiver's gender and caring for patients with metastasis) accounted for 12% of the variance in the QoL score (adjusted $R^2 = 0.12$, $F = 9.703$, $p < 0.001$) (Table 4).

The model for the support and economic impact subdimension initially included four variables that were selected based

on the bivariate analysis: education level ($p = 0.025$), employment status ($p < 0.001$), the average time of care per day ($p = 0.011$), and paying treatment-related costs ($p < 0.01$). The final regression model as shown in Table 4 included two variables (i.e., caregivers' employment status and average time of care per day), which accounted for 25% of the variance in the QoL score (adjusted $R^2 = 0.25$, $F = 22.456$, $p < 0.001$).

Discussion

This study aimed to evaluate the QoL of caregivers of women with cancer receiving cancer treatment and determine the predictors of their QoL. Most caregivers of women with a cancer diagnosis were female and had impaired QoL. The overall QoL of caregivers of women with cancer was associated with caregivers' gender, the average time spent for caregiving per day, and patients' cancer stage.

In the current study, 60.2% of the caregivers were women. In Turkey, the caregiving role mostly falls on women due to gender-related role expectations in the family (Gok Ugur & Catiker, 2019). Generally, women are responsible for caring for their children and spouse, doing chores, and fulfilling their professional job duties if they are employed (Sharma et al, 2016). Due to gender roles in some societies, such as Turkey, women are generally considered suitable for a caregiving role when a family member needs care. A systematic review of patients with cancer and their family caregivers showed that family caregivers were mostly female, taking this role without explicit communication with family members due to feeling obligated to take on this responsibility (Cai et al, 2021). Women caregivers for a patient with cancer, specifically women caring for male patients, might have high caregiving burden and be at increased risk of depression and anxiety (Geng et al, 2018; Govina et al, 2019). Despite this evidence on the role of gender in caregiving roles and its effect on caregivers (Cai et al, 2021; Geng et al, 2018; Govina et al, 2019), few studies have focused on caregivers of female patients with cancer.

In addition, this study showed that female caregivers with longer caregiving responsibilities per day experienced more impairment in their QoL. These findings reflect the heavy burden of caregiving on women as the female participants of the study had lower overall QoL than males; specifically, they displayed lower levels of QoL related to physical, psychological, and spiritual health and demonstrated a worse approach to diagnosis. Similarly, prior studies reported lower QoL among women caregivers of patients with cancer (Kaya et al, 2018; Ochoa et al, 2012). For example, Kim and Carver (2019) reported that female caregivers perceived their caregiving experience as more stressful and had lower QoL than men. Schrank et al (2016) also found that women felt significantly more burdened than men. These findings emphasize the need to focus on coping strategies with the cancer diagnosis and its treatment-related challenges among female caregivers. In addition, healthcare providers should provide psychosocial interventions tailored to the needs of the female caregivers of patients with cancer to improve their QoL.

In this study, not only the total duration of providing care to patients with cancer, but also the time spent for care per day was an important factor influencing the overall QoL, physical health, psychological and spiritual health, and support and economic impact among caregivers of women with cancer. Recent systematic reviews reported that the duration of caregiving is associated with caregiver burden and depression among caregivers (Geng et al, 2018; Lee & Lee, 2020). A study conducted in Turkey also showed that the QoL of caregivers who spent more than 3 hours per day providing care to their family members with cancer was significantly lower than those who spent less than 3 hours (Karakaya & Isikhan, 2020). Hence, it is important to develop interventions and provide services (e.g., home care services) to reduce the time spent per day for care to patients with cancer, thus decreasing the burden on the caregivers.

The findings of this study showed that providing care to women with metastatic cancer was associated with lower overall QoL, physical health, physiologic and spiritual health, and approach to diagnosis. Living with advanced or metastatic cancer often comes with a cost of burdensome physical and psychosocial symptoms and complex care needs for patients with cancer (Mollica et al, 2021). Addressing these needs for caregivers may bring more challenges as they also struggle to balance their life and their caregiving roles. While patients with advanced cancer often experience great uncertainty about their prognosis and fear of disease progression, they may need increased caregiver support (Mollica et al, 2021). Okcin et al (2012) found that caregivers have challenges from the time of diagnosis to the end of treatment related to the fear of cancer recurrence and metastasis. Similar to previous studies (Lee & Lee, 2020; Lim et al, 2017; Lund et al, 2015), this study showed that caring for women with metastatic cancer was a factor associated with higher impairment in QoL among caregivers. This suggests the importance of understanding the optimal role of caregivers in supporting women with advanced cancer receiving treatment (i.e., symptom management) and therefore finding solutions to reduce the burden or distress experienced by caregivers themselves.

In this study, employment status was associated with some dimensions of the QoL but not with the overall QoL. Being employed among caregivers was associated with lower QoL in the psychological and spiritual health status subdimension, but it yielded higher QoL in the support and economic impact subdimension. A systematic review also reported mixed findings on the association between employment status and caregivers' QoL (Ochoa et al, 2010). Social support and the economic status of caregivers are reported as determinants of caregiver burden (Nikbakht et al, 2022), and employed caregivers may have a better income level to better support patients with cancer (Ochoa et al, 2020). Nevertheless, Hastert et al (2020) found that employed caregivers experienced difficulties balancing work and caregiving roles associated with anxiety and depression. These findings may show that caregivers employed outside of the home may have financial sources to support their caregiving roles; however, they may find caregiving more challenging to maintain their psychosocial and spiritual health. Moreover, psychological and spiritual health status might be further exaggerated for caregivers without a private room in the home. This

suggests that caregivers who spend most of their time with the patient may not have spare time for themselves and have difficulty maintaining other responsibilities, thus impairing their social life and overall QoL (Lafci et al, 2020; Ochoa et al, 2020). Further studies are needed to understand the relationship among employment status, financial status, and the QoL of caregivers and therefore to find tailored solutions for those who struggle with the financial burden of cancer and the caregiving role for women with cancer.

Study Limitations

This study had some limitations. First, we recruited a convenience sample from one hospital in Turkey. Thus, the findings cannot be generalizable to all caregivers of women with cancer. Second, this study used a cross-sectional design, and therefore, we cannot conclude a cause-effect relationship between predictors and QoL. Finally, considering that the Turkish version of the QoL scale has different dimensions from its original version, the predictors may not be specific to the subdimensions but the overall QoL.

Conclusions and Recommendations

This study suggests that caregivers' gender, the average time spent for caregiving per day, and patients' cancer stage affect different aspects of the QoL among caregivers of women receiving cancer treatment in Turkey. Due to the dynamic nature of caregiving roles, longitudinal studies are required to understand the effect of providing care for women with cancer on caregivers' QoL over time. Furthermore, future studies are needed to find better solutions to support caregivers of women with cancer who are at high risk for impaired QoL by designing interventions tailored to their needs and preferences.

Ethics Committee Approval: Ethics committee approval was received for this study from the Koç University Ethical Committee (Date: February 7, 2020, NO: 2020.054.IRB3.026).

Informed Consent: Written informed consent was obtained from caregivers of women with cancer treatment who participated in this study.

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